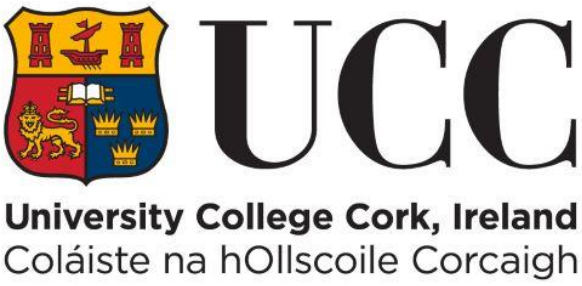

End-of-Life Care Supports and Decision making Practices in Specialist Intellectual Disability Residential Services

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List of Abbreviations

Assisted Decision Making (Capacity) Act	ADM
Clinical Nurse Manager	CNM
Community Palliative Care Team	CPCT
Convention on the Rights of People with Disabilities	CRPD
Do Not Resuscitate	DNR
European Convention on Human Rights	ECHR
General Practitioner	GP
Health Service Executive	HSE
Health Information and Quality Authority	HIQA
Intellectual Disability	ID
Irish Medical Council	IMC
Law Reform Commission	LRC
National Consent Policy	NCP
Not for Resuscitation	NFR
Nursing and Midwifery Board of Ireland	NMBI
Occupational Therapist	OT
Principle Contact Person	PCP
Senior House Doctor	SHO
Speech and Language Therapist	SLT

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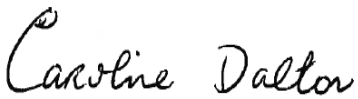
Declaration

I declare that the content of this thesis is entirely my own work and it has not been submitted for a degree at this or any other University.

Where the work of others has been used to augment this thesis, it has been referenced accordingly.

Signature:  **Date:** 04/10/2019

Dedication

To Mum and Dad

Acknowledgements

Firstly, I wish to thank my supervisors, Dr. Joan McCarthy and Dr. Nicola Cornally for their constant support, professionalism, and encouragement through this PhD process. My interactions with both of you over the course of this study, have motivated and encouraged me to keep going. The commitment you have shown to the development of this dissertation has been immeasurable and you both became *"fellow travellers"* on my journey, patiently waiting as I wandered down blind alleys, and providing much needed guidance on how to find my way back out. Most of all thank you for your kindness and empathy, which was also much needed at times.

This study would not have been possible without the commitment shown by the Principle Contact People within each of the three organisations in this study. Every effort was made to provide me with access to the documentation and individuals I needed to contact along the way. I will always be grateful for the words of encouragement and the endless cups of tea, that appeared as I worked my though each case file.

I will also be forever grateful to the families who participated in this study. For many, the conversations we had were not easy, and yet all those involved persevered. Most importantly thank you for allowing me to get to know Jennifer, Johnny, Finbarr, Charles, Frank, Louise, Joanne, William and Arthur. To the health professionals involved, who gave so freely of their time and insights into the care of people with ID, thank you. Your ongoing commitment and determination to support people at end of life, even when faced with significant obstacles is humbling.

And finally, to my crew!! Derry, Chloe and Ruairi, thank you keeping the ship afloat, and making sure no one fell overboard!!

Abstract

Background: Over the past 50 years, the profile of people with intellectual disability (ID) has changed because they are living longer with a wide range of co-morbid conditions, which impact on both their cognitive and physical abilities to engage in conversations about end-of-life care. Coupled with this, people with an ID are being supported in community settings and are availing of supports from community and hospital services. In addition, the Assisted Decision Making (Capacity) Act (ADM) (2015) is changing the way these individuals will be included in decision making across all aspects of their lives into the future. These changes have led to an increased interest in the end-of-life care of people with an ID and how end- of-life decisions are made with this population.

Aim: This study describes and analyses end-of-life care supports and decision making practices in specialist ID residential services.

Methods: Case study methodology was used to develop a detailed account of how nine people with an ID were supported at the end of their lives. A multiple-embedded case study design was used, drawing on a range of data sources and multiple perspectives including those of family members and healthcare professionals, and the case files of nine decedents identified in this study. Qualitative content analysis techniques were used to analyse the data gleaned from documents, and interviews. Data identified from three questionnaires was also analysed qualitatively. Following the analysis of the nine individual case studies, cross case analysis was used to identify commonalities and differences between the cases.

Findings: Analysis of these nine cases has identified a number of factors of importance to the end-of-life care of individuals with an ID from the perspectives of families and staff supporting them.

Firstly, specialist ID services are committed to supporting people with an ID at end of life, and to providing services which allow them to *"age and die in place".* Where this could not be achieved, supports were provided in external services such as hospitals and hospices, reflective of an ongoing commitment to the person at end of life.

Secondly, this commitment is also reflected in the support provided to the decedents in this study by family members and ID staff who were involved in their care. Those individuals, who formed a circle of support around the decedents used their collective knowledge to promote the autonomy of people with an ID and actively advocated on their behalf.

Thirdly, despite the evident commitment of all involved, issues arose in relation to the provision of end-of life care at organisational and individual levels. These issues included a lack of preparedness in both specialist ID residential services and acute hospital settings to support people with an ID at end of life. A culture of silence was also evident in specialist ID residential services: there was a lack of conversations about death and dying in general as well as discussions about end-of-life care in particular, with the decedents involved. This culture of silence prevented people with an ID from being informed that they were dying.

Finally, this study also determined that people with an ID are not included in decision making about their end-of-life care, the responsibility for which was borne by family members and health professionals across a range of services.

Conclusion: Given the changing age profile of people with an ID, the landscape in which health services are provided, and the legislative changes envisioned in the ADM (2015), issues relating to communication, capacity and decision making for people with an ID must be addressed. People with an ID and their families should be included in end- of-life care at a much earlier stage than is currently the case. The supports required by people with an ID, their families and staff need to be made explicit to ensure the autonomy of people with an ID is protected and promoted when making end-of-life decisions. There is potential for person centred planning processes, within specialist ID services, to be used to ensure conversations about death, dying and end-of-life care occur in a timely manner.

Overview of Thesis Chapters

The aim of this study is to describe and analyse end-of-life supports and decision making practices in specialist intellectual disability (ID) residential services. This thesis is presented in seven distinct chapters. In Chapter one, I present the background to the study, focusing on the issue of death, dying and disability rights, and cause and age of death in the ID population. The chapter concludes with a discussion of the current status of end-of-life research in this population and my own personal interest in undertaking this study.

Chapter two presents theoretical perspectives relating to autonomy, capacity, consent, and decision making at end of life from an ethical and legalistic perspective. The principle of relational autonomy, and its legal expression in a functional approach to capacity is a central tenant of this thesis. Therefore, an exposition of policies and legislation relating to capacity, consent and advance care planning is presented.

Chapter three presents a narrative review of the empirical literature relating to end-of-life care and decision making practices in the ID population. Emerging areas of knowledge relating to the inclusion of people with an ID in their end-of-life care and the perspectives of families and staff working in ID services when supporting the person at end of life are delineated. The impact of issues relating to death, dying and end of life discourse are explored. Approaches to decision making at end of life are also presented.

In chapter four the case study methodology approach used in this study is presented. The aim and objectives of the study are outlined, along with a detailed account of the research design, and sampling approach used. The data collection and analytical techniques used are then described, along with the ethical considerations relevant to this study.

The findings and cross case analysis of the nine cases studies identified in this thesis are presented in chapters five and six. Initially, I present contextual information relating to the organisations involved, followed by the demographic data of the descendants, their family members, and healthcare professionals involved in this study. I then present the individual case studies which outline the end-of-life care of the nine deceased individuals, who were supported in specialist ID residential services. A cross case analysis is then undertaken with a specific focus on themes relating to commitment to providing end-of-life care, communicating death related bad news and factors impacting end-of-life decision making.

In chapter seven, the findings of this dissertation are discussed, and this study concludes by identifying the implications of this study in terms of education, and clinical practice in specialist ID residential services. The strengths and limitations of the study are also presented, along with recommendations for further research in this area.

Chapter 1: Background

Introduction

The overarching aim of this study is to describe and analyse end-of-life supports and decision making practices in specialist ID residential services. This chapter describes how end-of-life care is understood and contextualised in this study and highlights issues relating to disabilism, death in disability discourse, cause and age of death, and the current status of end-of-life research in the ID population. I will also present my own personal and professional motivation for undertaking this study.

1.1 End-of-Life Care

In developing and contextualising my understanding of end-of-life care, I was informed by two specific definitions. The first definition developed by the Department of Health (2008, p.47) defines end-of-life care as:

> *"Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support".*

The second definition proposed by Radbruch & Payne (2009, p.282) states that:

> *"End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness"*

These two definitions combined, reflect a biopsychosocial perspective of end-of-life care in conjunction with the recognition of the role of both families and staff supporting the person who is dying. This speaks to a holistic and person centred approach to end-of-life care, in keeping with the ethos of person centredness, which is fundamental to ID specialist services. Therefore, for the purposes of this study, end-of-life care is understood as the biological, psychological, social, spiritual, and practical support provided to individuals in the 24 months prior to their deaths. The fundamental role played by families and staff in specialist ID services in providing this care is acknowledged.

1.2 Disability Rights

Any discussion of the end-of-life care of people with an ID, firstly, must acknowledge that individual perceptions of what it is to have a disability, and the quality of that life, can vary greatly. Having a disability can impact on the way people are viewed and treated, often referred to as disability bias or disabilism.

Disabilism has led to people with disabilities being viewed as a stigmatized minority (Longmore, 1995), who historically, were segregated from society and supported in institutions. These individuals were perceived as having little scope for personal development and were viewed as having a poor quality of life (Robins, 1992). People with an ID had few rights and little control over their lives and were segregated to the extent that they were almost forgotten about by society in general (Freyhoff et al. 2003).

However, during the 1950's the manner in which services were provided to people with disabilities changed. The catalyst for this change was the *"concept of normalisation"*[1] as defined by Wolfensberger (1972). The focus of this concept was on ensuring that people with an ID could live their lives, in as culturally normative a way as possible. In conjunction with this, the Fourth World Congress of the General Assembly of Human Rights, defined its General and Specific Rights of the Mentally Handicapped, which were accepted by the United Nations in 1971. This focus on the rights of people with a disability, led to the development of the disability rights movement, which continues to press for change in the lives of these individuals.

For individuals with an ID, the emergence of the disability rights movement was instrumental in addressing disabilism, by promoting the autonomy and other human rights of people with disabilities. The importance of the right of autonomy for people with an ID is reflected in three distinct phases of the disability movement, referred to as waves (Bersani, 1996). The first wave is identified as the professional wave, the second wave is referred to as the parent wave and the third wave refers to the self-advocacy wave

The first wave, according to Bersani, (1996) occurred during the mid-19th to mid-20th century, when people with an ID had little control over their lives. Their fates were largely in the hands of professionals such as doctors, psychologists and social workers. At this time, professionals spoke:

> *"not so much for or with the individual in his or her charge, but rather about him or her, from a distanciated, objective position"* (Owen & Griffiths, 2009, p. 102).

The medical model of disability defined disability as the experience of physical and psychological defects, which must be cured to address the needs of afflicted persons (Longmore, 1995). Such individuals were viewed as people who needed to be fixed; services were often provided by charities, and were focused on protecting these individuals who, it was assumed, could not take care of or make decisions for themselves (Bach & Kerzner, 2010).

[1] "*Utilisation of means which are as culturally normative as possible, in order to establish, and/or maintain personal behaviours and characteristics which are as culturally normal as possible".* (Wolfensberger, 1972)

However, during the 1950s, people with ID and their supporters, more specifically their parents, and families, began to reject this perception of people as sick and aligned themselves with the ethos of viewing disability through the lens of celebrating human differences and variation (Helm & Friedman, 2010). Families began to advocate on behalf of their loved ones, demanding a more personalised approach to caring be taken. This second wave was evident in an Irish context in the formation of Parents and Friends Associations, which were lay organisations established to meet the needs of families who did not wish to avail of institutional care. These local organisations expanded rapidly throughout Ireland during the 1960s, raising awareness of disability at a societal level and leading to an increase in disability services (Department of Health, 1960). This initial development of advocacy within ID services then continued, to embrace the concept of self-advocacy.

Self-advocacy, the third wave of the disability movement, developed during the 1970s and 1980s with the realisation that people with an ID could, and therefore should, be enabled to speak for themselves. According to Owen & Griffiths, (2009, p. 103) the self-advocacy movement necessitates

> *"a mode of dialogue that we take to be fundamental to the constitution of autonomy and self-determination".*

The importance of appropriate communication, and reasonable accommodation, are identified in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This form of dialogue requires respectful communication to occur, cognisant of the augmentative and alternative forms of communication, used by people with an ID. It also requires that reasonable accommodation is made to provide the necessary supports to ensure people with an ID, can exercise their rights on an equal basis with others. This can be achieved through the provision of person centred and culturally competent support, which promotes autonomy and independence (Helm & Friedman, 2010). The disability rights movement continues today in its quest to ensure people with an ID are treated with respect, and experience equity in their daily lives.

1.3 Death in Disability Discourse

The movement to a rights based perspective of disability, and the rejection of the *"sick role"* has had an impact on the inclusion of *"death"* in disability discourse for several reasons. Firstly, according to Todd (2007), there has been a long association between disability and the metaphor of death. During the 18th and 19th centuries, the Eugenics Movement sought the segregation of people with an ID from society in general. During this time, many people perceived as deviant such as "imbeciles", pregnant women and girls, the destitute and the mentally ill were institutionalised with no real chance of ever returning to their communities (Shanley, 1986).

Within these institutions, these individuals experienced a social death, long before their biological death occurred. Todd, (2007, p229) states that such institutions could easily be

> *"viewed as social cemeteries, places to which parents were once asked to send their offspring and to think of them as having died".*

Secondly, people with disabilities were fighting the perception that people are *"better off dead than disabled".* In the United States of America (USA) for example, the slogan *"Not Dead Yet"* became associated with the disability rights movement, and the move away from the *"medical model"* perspective of disability (Runswick-Cole, 2010). Thirdly, the metaphor of death has also been linked to the diagnosis of a child's disability, where the reaction of parents to the diagnosis has been likened to the grieving process where the parents must adjust, and learn to accept, their child's disability (Runswick-Cole, 2010).

These factors, while important for change, created a pendulum shift, resulting in the exclusion of death from disability discourse, leading to the issue of death becoming taboo (Todd, 2007) and, by extension, leading to a lack of discussion of death and dying and end-of-life care in the ID field. Todd (2007) stated that this taboo needs to be addressed, as the impact of an ID will exert the same influence on the death, as well as the life, of the individual. Todd et al. (2013) contends that the field of ID has largely been *"resurrectionist"* in nature, supporting those perceived as socially dead. The culture and focus of ID services has been built around enabling and facilitating life and ensuring the inclusion of people with an ID in their own communities. According to Todd et al. (2013), providing end-of-life care was not viewed as being within the remit of such services, but this is now changing.

While it is acknowledged that many gains have been made with respect to social inclusion and life expectancy for people with an ID, Helm & Friedman (2010) contend that more needs to be done to improve the lives of this population, especially within the context of end-of-life care. They further contend that while people with an ID will encounter similar end-of-life issues as the neuro-typical population, they also experience many unique challenges that require consideration. Some of these unique challenges are reflected in the age and cause of death of people with an ID and these factors will be explored in the following section.

1.4 Cause and Age of Death in the Intellectual Disability Population

At the outset, it is important to state there is a dearth of information relating to mortality in the ID population, both nationally and internationally. Several factors contribute to this lack of information, for example, many countries have incomplete registers of people with an ID such as the USA (Lauer & McCallion, 2015) and the United Kingdom (UK) (Heslop et al. 2015). While Ireland does maintain a register, it is comprised of information relating to people who are known to specialist ID services.

It is accepted, that not all those with an ID avail of these and are therefore not registered with the database. However, despite this issue, the National Intellectual Disability Database (NIDD) provides comprehensive annual statistics specific to the ID population in Ireland. According to 2017 figures, there are 28,388 people registered on the NIDD, representing a prevalence rate of 5.96 per 1,000 populations, based on 2016 Census of Population figures.

Despite the issues in accessing mortality data, studies have been undertaken relating to age and cause of death in this population. These studies have been undertaken across a number of jurisdictions including the UK (Heslop et al. 2015), the USA (Lauer & McCallion, 2015), Australia (Florio & Trollor, 2015) and Ireland (McCarron et al. 2015) and will now be considered.

1.4.1 Cause of death in the intellectual disability population

A number of health conditions have been identified, as of particular significance in the cause of death of those in the ID population. Across all studies, respiratory illness was one of the leading causes of death ranging from a reported rate of 52% in the UK (Glover and Ayub, 2010) to a rate of 20% of cases in Australia as indicated by Trollor et al. (2017). Hosking et al. (2016) found that cause of death for pneumonia and aspiration pneumonia were ten times higher in those with an ID, when compared to the neurotypical population. Circulatory disease was also a significant cause of death and was identified as the most prevalent cause of death across three UK based studies (Heslop et al. 2014; Hosking, 2016; Glover et al. 2017).

Cancer has emerged as a significant factor, in the cause of death of people with an ID (Tyrer & McGrother 2009; Glover et al. 2017; McCarron et al. 2018), who typically present with cancers of the digestive system such as gastrointestinal and colon cancer. This contrasts with the forms of cancer found in the neurotypical population where lung, breast and prostate cancers are more evident. Cancer deaths in the ID population are lower than that of the neurotypical population which Glover and Ayub (2010), suggests may be due to lower rates of smoking and lower life expectancy reducing the risk of people with ID, reaching an age where they might be at risk of developing cancer.

The lack of a standardised procedure for reporting mortality across countries and the limited amount of research undertaken, makes it difficult to draw definitive conclusions as to the cause of death of people with an ID. However, it is clear, over the past decade, that respiratory and circulatory conditions play a significant role in the deaths of people with an ID, and that concerns regarding the impact of cancer in this population are increasing.

1.4.2 Age at death in the intellectual disability population

Of the studies undertaken relating to age at death, the majority have been undertaken in the UK (Hogg et al. 2007; Tyrer & McGrother 2009; Glover and Ayub 2010; Heslop et al. 2014; Hosking et al. 2016; Glover et al. 2017), Ireland (Lavin et al. 2006; McCarron et al. 2018), the USA (Lauer & McCallion 2015) and Australia (Florio and Trollor, 2015).

Lauer & McCallion (2015) explored the mortality of people in the USA and found that people with an ID, across the lifespan, had a lower life expectancy (50.4-58.7 years) than people in the neurotypical population (78 years). The authors conclude that the life expectancy of people with an ID, is still approximately 20 years less than those in the neurotypical population, a finding also reflected in the findings of Emerson et al. (2014). This UK study explored the mortality rates of people in the Sheffield Case Register (SCR) over a 33-year period from 1980-2012. For the neurotypical population there was a steady rise in life expectancy from 74 to 81 years. For those with an ID, life expectancy rose from 51 years to just over 60 years. A recent UK study undertaken by Hosking et al. (2016) has identified that the gap between the mortality rates of people with an ID and the neurotypical population is not closing. This disparity is also evident in the USA and Australia (Lauer and McCallion, 2015; Florio and Trollor, 2015).

From an Irish perspective, Lavin et al. (2006) concluded that the lifespan of people with an ID decreased as the level of the severity of their ID increased. A subsequent Irish study, undertaken by McCarron et al. (2015), found that while people in the neurotypical population, on average, die at the age of 74; for people with an ID, this was reduced by 19 years, to the age of 55. People with a mild ID, on average died aged 60, those with a moderate level of disability died at the age of 62. The average age of death was lowest for those with a severe ID, who died at the age of 54, followed by those with a profound level of ID, who die at the age of 44.

Several trends can be identified from the literature. Firstly, there has been a sustained improvement in the life expectancy of people with an ID, nationally and internationally (Lavin et al. 2006; Emerson et al. 2014; Heslop, 2014; Lauer & McCallion, 2015;). However, within an Irish context, McCarron et al. (2015) are concerned that no further sustained increases in longevity have been identified during the 10 years of their study. Glover et al. (2017) claim that the mortality rate of people with an ID in Ireland is higher than in the UK, which is a cause of concern from an Irish perspective. Despite the improved longevity in the ID population, there is still a substantial gap of up to twenty years between the life expectancy of people with an ID, and those in the neurotypical population across the UK (Emerson et al. 2014), Ireland (McCarron et al. 2015) and the USA (Lauer & McCallion, 2015).

1.5 End-of-Life Care Research in the Intellectual Disability Population

Over the past two decades, despite an increased focus on and discussion of end-of-life care in the ID population, there is a dearth of research in this area. Most recently the European Association for Palliative care (EAPC), established a taskforce to identify what happens to people with an ID at end of life and the problems encountered by people in relation to death and dying (Tuffrey-Wijne & McLaughlin, 2015). It was the intent of the taskforce to identify best practice across Europe as a mechanism to show how services, and individuals supporting people with an ID, had managed to meet best practice standards. However, the lack of research in the field of ID and end of life, made it impossible for the taskforce to present specific guidelines, and so consensus norms were presented instead.

In addition to issues specific to end-of-life care, there is also a dearth of policies and guidance in relation to end-of-life decision making, and advance care planning to support relevant stakeholders. While both Johnson (2010) and Kingsbury (2010) suggest that advance care planning can be incorporated into a person centred planning process there is, overall, a lack of policies and supportive guidance in relation to implementing advance care planning with the ID population (D'Haene et al.; Voss et al. 2017). D'Haene et al. (2010) explored the availability of end-of-life policies to support and guide individuals within eighty-four organisations. Voss et al. (2017), undertook a systematic review of advance care planning for people with an ID. In both studies, it was identified that the majority of organisations do not have any policies in place. Where such policies existed, they were mainly linked to medical decisions such as DNRs, withdrawing/withholding treatment and euthanasia.

Additionally, even where policies existed, D'Haene et al. (2010) found that few documents explored distinctive aspects of end-of life care and stated it was not possible to identify how end-of-life decisions were made in these services. This finding is reflected in the findings of Wagemans et al. (2010) who also found that in many cases there was no clear decision making process identified when providing end-of-life care to people with an ID. This, according to Kingsbury, (2010) has led to a lack of understanding of the role of people with an ID and significant others in the decision making process.

1.6 Research Interest

Since registering as an intellectual disability nurse (RNID) in 1994, I have participated in ongoing changes in specialist ID services, as they evolved from institutionally based residential services, to congregated settings and as they continue to evolve into community based services. Throughout these transitions, I have striven to ensure these services were evolving to meet the needs of people with an ID and the staff supporting them.

Whilst I have worked as a lecturer within the university setting for the past ten years, I have maintained my links with several specialist ID services. I have ongoing interactions with clinical colleagues, as well as past and current students in relation to issues they encounter within these settings. In addition, I am a member of the education committee attached to the All-Ireland Institute of Hospice and Palliative care in Ireland and have contributed to research studies funded by the Irish Hospice Foundation, to ensure that issues relating to people with an ID, are included in national studies.

Over this time, from both an educational and clinical perspective, the changing needs of an ageing ID population have become apparent. As specialist ID services have developed and adapted to meet the needs of service users, the issue of end-of-life care was one I was consistently called on to address by both clinical colleagues and ID nursing students both in terms of end-of-life education and guidance from a service perspective. These conversations in conjunction with my own observation of the changing landscape of ID specialist services, provided the impetus for my increasing interest in end-of-life care in general. As previously mentioned, I have also engaged in research studies, the most recent of which focused on people with dementia and ethical decision making in end-of life care. (McCarthy et al. 2016). In this study, I focused on including a case relating to a person with dementia and an intellectual disability This ongoing interaction with the research in this area, and ID specialist services led me identify a need for research to be undertaken focused on end-of-life supports and decision making practices in specialist ID residential services.

Conclusion

It is evident from the preceding sections, that the way services are provided for people with an ID has changed considerably in the past fifty years. The disability rights movement, from the 1950s onwards, has worked to ensure that people with an ID are no longer cared for in segregated institutionalised settings. Many of these settings are now closed, and people with an ID are supported in integrated community settings. This change in the focus of care of people with an ID led to the rejection of the medical model of disability. This had the inadvertent consequence of causing the issue of death and dying to become taboo, in the field of ID.

In tandem with this change, while people with an ID still have a higher mortality rate than that of the neurotypical population, there has been a sustained improvement in the life expectancy of the population. The age profile has changed over past decades, with those aged thirty-four years and over increasing from 29% to 44% of the overall ID population since 1974 (Kelly et al, 2010). With this increase in life expectancy, many of this population are experiencing prolonged life-limiting illnesses, such as respiratory and cardiovascular disease, Alzheimer's and cancer (Patja et al. 2001; McCarron et al. 2018).

This changing profile has led to an increased demand for services equipped to meet the needs of older individuals with ID (Kelly et al. 2010). Given this change in demographics and health needs, provision of end-of-life care has increasingly become an issue which must be addressed. Organisations supporting people with ID are now challenged to meet end-of-life care needs and address associated issues (Ryan et al. 2011).

However, despite a renewed interest in the provision of end-of-life care, little is known about how it is provided to people with an ID. Studies have identified that there is limited research available, relating both to end-of life care and advance care planning (D'Haene et al.; Voss et al. 2017). Such was the dearth of research and other forms of documentation relating to end-of-life, uncovered by the EAPC in 2015, that the taskforce declared that people with an ID were an "*invisible population"* (Tuffrey-Wijne & McLaughlin, 2015).

The taskforce further identified the need for research to address this lacuna, including the need to explore where people with ID die, who supports them, the perspectives and experiences of people with ID, families, carers and professionals and factors which influence decision making. This study goes some way to address the research needs identified, as the aim of this study is to describe and analyse end-of-life supports and decision making practices in specialist ID residential services.

Chapter 2: Autonomy, Capacity, and Decision making Practices

Introduction

The purpose of this chapter is to explain the concepts of autonomy and capacity, from a philosophical perspective, and explore their ethical and legal application to the lives and deaths of people with an ID. I turned to the seminal work of Beauchamp and Childress (1979), in reviewing the theoretical literature relating to autonomy, capacity and decision making. From an Irish perspective, the work of McCarthy et al. (2011), Donnelly (2016; 2010) and the Law Reform Commission (LRC) (2005) is also explored, along with other literature in this area.

This chapter begins with an introduction to the concept of autonomy and related responsibilities. These include respect for autonomy and autonomy as a negative and positive obligation. Factors of significance in the application of the right of autonomy to the ID population will then be explored. Following on from this, I explore the concept of decision making capacity from both an ethical and legal perspective, as well as its application to the ID population with emphasis on the functional assessment of capacity especially as it might pertain to end-of-life decision making.

2.1 Defining Autonomy

Beauchamp and Childress (1979), identified four basic principles of bioethics as autonomy, beneficence, non-maleficence and justice. The principle of autonomy refers to the right of individuals to hold their own views and beliefs and to make decisions and take action based on these values and beliefs. The principle of beneficence manifests in the form of actions which are deemed to be of benefit to others. Non-maleficence is reflected in the obligations of health professionals not to cause harm and to prevent harm. The concept of justice refers to the fair, equitable and appropriate distribution of resources or protections.

Whilst acknowledging the importance of the aforementioned principles, the principle of autonomy is of specific focus in this thesis due to the interconnectedness of autonomy, decision making and the circumstances in which consent is given. In beginning this review of autonomy, capacity and decision making practices, I agree with the perspective of Beauchamp and Childress (2013), that all four principles are equally significant in clinical practice. This means that health and allied professionals must weigh their obligations in relation to each of these principles and to the particular contexts within which they arise. Within the health care system, the principles of beneficence, non-maleficence and justice may sometimes bring healthcare professionals into conflict with the principle of autonomy. This conflict, for example, may arise with respect to beneficence, where health professionals are deemed to be paternalistic towards their patients/clients and are perceived as undermining the autonomy of these individuals.

For example, research in the field of ID consistently shows that professionals do not have conversations with people about death and dying, out of a need to protect them (Ryan et al. 2011; Tuffrey-Wijne et al. 2017).

Justice may come into conflict with autonomy with respect to the rationing of resources, where resources may have to be used to meet the needs of many, as opposed to the preferences of a few. Specific to those with an ID, Johnson (2010) highlights the concept of justice, in moderating the impact of disabilism. Johnson (2010) contends that the assumptions and perceptions of health professionals of what it is to have a disability and the quality of that life, can vary greatly. Stein and Kerwin (2010), suggest that the attitudes of health professionals towards disability, may determine whether a life sustaining treatment is provided to an individual or not. However, they conclude that justice would demand that, when accessing treatment, people with an ID should be offered the same range of treatments as everyone else - the person's level of functioning should be considered a separate issue to the treatment of an acute health issue. For Johnson (2010), it is imperative that the assumptions and perceptions of those involved are recognised and the impact that any prejudicial beliefs have must be recognised and kept in check.

Returning to Beauchamp and Childress; they understand autonomy as:

> *"a form of personal liberty of action in which the individual determines his/her own course of action in accordance with a plan chosen by himself/herself"* (Beauchamp and Childress 1979 p.56).

For Beauchamp and Childress (2013), autonomous actions can be defined as involving (1) intentionality, (2) understanding and (3) non-control or voluntariness.

Intentionality

Intentionality or purposefulness according to Beauchamp and Childress (2013, p. 105) *"is not a matter of degrees"*. An act is either intentional or it is not. For an act to be considered intentional, a specific plan needs to have been put in place to bring about a desired outcome. However, it must be acknowledged that the desired outcome may not always be attained.

Understanding

An individual must understand an action if that action is to be considered autonomous. An individual must be capable of understanding and appreciating his or her circumstances, be provided with pertinent information relating to the options available to them and undertake a cost/benefit analysis of these options.

In addition, the individual must have the capacity to understand which option is most likely to produce the desired or expected outcome. Where understanding is limited, it is likely that the decision made by the individual may have an unintended outcome and therefore the decision cannot be considered autonomous.

Non-control or Voluntariness

Non-control or voluntariness is a concept similar to the concept of liberty; it is basically the freedom to act. Being free of controlling influences ensures individuals can do as they wish, or equally ensures an individual cannot be forced to do something, he/she does not want to do. Controlling influences can be external to the individual, such as the influence of another person, or a policy. Such influences can also be internal to the person, such as the impact of physical or psychological ill health. Beauchamp and Childress (2013), further state that not all influences in a person's life are controlling; for example, some health professionals may use their influence to facilitate or enhance autonomous decisions in those they support. In contrast to their perspective on intentionality, Beauchamp and Childress (2013), contend that an individual need only have a substantial degree of understanding and freedom from control, to make an autonomous decision. These authors submit that understanding and non-control exist on a continuum, ranging from full understanding to no understanding and complete non-control to full control. The authors further contend that a line must be drawn to determine adequate degrees of understanding and control specific to the decision being made at the time. The authors identify the need for threshold markings to be used, to establish if a decision is autonomous or not.

2.2 Relational Autonomy

Some philosophers suggest that the principle of autonomy has been given too much weight in the realm of healthcare decision making (Beauchamp and Childress, 2013). Callahan (1998 p.41), states that;

> *"Autonomy buys our freedom to be ourselves and to be free of undue influence by others at too high a price. It establishes contractual relationships as the principle and highest forms of relationships. It elevates isolation and separation as a necessary starting point of human commitments".*

While in western countries, personal freedom, self-determination and independence are highly valued, this is not true for all cultures or ethnic groups (Yeo et al. 2010). The importance of nurturance and empathy and being cognisant of the needs and specific situations of each individual, and their concern with the welfare of others must be recognised.

According to McCarthy et al (2011), feminist ethicists identified the impact of gendered roles and understanding on autonomy and, in so doing, widened the scope of ethics and decision making to include the sociological, cultural and political factors which influence autonomous decision making in healthcare settings. Ethicists, such as Sherwin (1998), claim that the liberal, highly individualised, westernised perspective of autonomy should be replaced with one that takes more account of wider social relationships. This perspective of autonomy, referred to as *"relational autonomy"*, gives recognition to the view that people are not always motivated by self-interest but are motivated by their attachment to, and solidarity with, others (McCarthy et al. 2010; 2011). In essence, relational autonomy embraces the idea that people are social beings, whose choices and decisions are enabled and facilitated in the context of their social circumstances. Therefore, the scope of ethics and decision making needs to widen to include the sociological, cultural and political factors which influence and enable the decision making of individuals.

The notion of relational autonomy also recognises that an individual's identity is to some degree a product of his or her social relationships; they share goals with their local communities, but these goals can change as people reflect on what is of importance in their lives. Whilst acknowledging the interdependency of human beings and the importance of social relationships, Beauchamp and Childress (2009,) alert us to the dangers of oppressive social relationships and social norms which can compromise autonomy and which according to McCarthy et al. (2011) prevent the development of the core competences required to facilitate decision making, namely self-trust, self-understanding and self-worth.

While it is important to be mindful of the negative influence of coercive or over controlling relationships, it is also of importance to recognise that positive, respectful relationships can foster and promote the autonomy and capacity of individuals. Within a healthcare context, these relationships could be developed between health professionals, patients and service users and their families in a manner which ensures that decisions are made *"with"* as opposed to *"for"* the individual involved.

2.3 Respect for Autonomy in Healthcare Settings

Specific to the healthcare setting and end-of-life care, McCarthy et al. (2011) state that in recent years, there has been increased attention internationally, on ways and means to transform how illness is managed and end-of-life care is provided. There is a specific focus on patient directed and patient focused care as an expression of patient autonomy which is understood as both a negative and positive right. While often linked to the right to refuse medical treatment (negative right), an individual's right of autonomy also extends to making decisions on the form of treatment to be undertaken, how treatment should proceed and the environment in which treatment should occur (positive right) (McCarthy et al. 2011).

The concept of respect for autonomy is also discussed as both a negative and positive obligation. As a negative obligation, Beauchamp and Childress, (2013, p. 107) assert that:

> *"autonomous actions should not be subjected to controlling restraints by others"*

although they do acknowledge that there will be valid exceptions to this in practice (these limits will be explored in greater detail in section 2.4 below). Beauchamp and Childress (2013, p. 104), also describe autonomy as a positive obligation which;

> *"requires both respectful treatment in disclosing information and actions that foster autonomous decision making"*.

The authors further state that the ability of individuals to make autonomous decisions, requires the co-operation of others. Within the healthcare setting, respect for autonomy requires that professionals make individuals aware of the options open to them, disclose information, ensure understanding and voluntariness and promote the individual's ability to make decisions. Beauchamp and Childress (2013), also caution that respecting autonomy does not mean that individuals have *"a duty"* to choose; rather they have the *"right"* to choose. It is not mandatory for individuals to take on board information provided, or to make decisions based on this information.

It would, in fact, impinge on an individual's autonomy to force them to make choices and decisions, or give them information against their will. The authors suggest that it behoves health professionals, to identify the perspective of the individual with respect to receiving information and making choices and to proceed in accordance with the individual's expressed preferences.

2.4. Limitations of Autonomy

Although the right of autonomy is highly valued by individuals and wider society, it is not an absolute right - there are limits to autonomy. In some instances, these limits arise due to our obligations to others and are reflected in the concept of justice and the protection of third parties (Donnelly, 2010). Firstly, the concept of justice is often discussed within the context of health care. The health care system is a finite resource and the mantra of *"value for money"* can cause real tension as rationing resources may mean that not all patients will get what they want or need. Limited resources can change the care provided; a service may not be able to meet even the basic needs of one patient if all available resources are used to meet every wish of another. In this situation, meeting the basic needs of individuals must supersede meeting the wishes of every patient/client (Yeo et al. 2010).

Secondly, when exercising one's right of autonomy, it is generally accepted that one cannot unduly interfere with the lives of others. Specifically, it is usually viewed as acceptable to limit individual autonomy in specific circumstances, such as when there is a danger of potential harm to other individuals or to public health (Beauchamp and Childress, 2013; Donnelly, 2010). While what has become known as Mill's *"principle of harm"* is widely accepted in situations where, for example, a person is violent and threatening to harm others, in other situations it is not so clear cut (Mill [1859] 1975). Where issues arise in identifying if a credible risk exists and/ or the potential degree of harm, then to what extent can one limit another person's liberty? This issue can arise in the field of ID where physical or chemical restraint has been used to manage aggressive behaviour for protracted periods of time (Edwards et al. 2018).

In other instances, limits can arise because of the impact of the exercise of autonomy on the well-being of the individual themselves. Mill ([1859] 1975), suggests that it is not sufficient to constrain a person's autonomy for his/her own good. However, this can lead to major professional, ethical and personal dilemmas for healthcare professionals. For example, if an individual makes an autonomous decision to end his/her own life, this can leave professionals in difficult situations with respect to the duty to care, beneficence and non-maleficence, as borne out in Fleming v. Ireland [2013] IESC 19.

2.5 Autonomy in an Irish Context

In the past decade, and in line with other western countries, Irish government policy documents and professional codes reflect an increased focus on the involvement of individual patients/clients in their own care (McCarthy et al. 2011). For example, according to the Health Service Executive (HSE), (2008, p.6):

> *"[I]nvolvement" is a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change".*

This focus on patient/client directed care is identified in the Irish Medical Council (IMC, 2016) *Guide to Professional Conduct and Ethics for Registered Medical Practitioners* which documents the right of patients/clients to be viewed as autonomous individuals. It is also identified in the Nursing and Midwifery Board of Ireland (NMBI) (2014) *Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives.*

Several resources aimed at health professionals and clinical practice have also been developed by Irish organisations and academics. The Health and Information and Quality Authority (HIQA, 2016), published a guide for health professionals entitled, *Supporting people's autonomy: a guidance document*. This document outlines a six-step process for promoting autonomy in residential settings. These steps include (1) respecting the person's right to autonomy, (2) avoiding pre-judging individuals, (3) communicating appropriately, (4) balancing rights, risks and responsibilities, (5) agreeing person centred supports and (6) evaluating supportive activities. McCormack and McCance (2010) also developed the *Person-Centred Nursing Framework*, which is focused on the provision of person-centred care, underpinned by the principles of dignity, respect and autonomy. This framework provides guidance for frontline staff who wish to promote the autonomy of those they support at both an organizational and individual level. Further detailed guidance specific to promoting autonomy at end of life is provided by McCarthy et al. (2011) who developed *An Ethical Framework for End-of-Life Care*, a set of ethical and legal resources aimed at developing sound clinical practice in end-of-life care in Ireland. In 2016, an additional resource, *Ethical decision making in End-of-Life Care and the Person with Dementia*, was developed by McCarthy et al. (2016) which focused on developing resources to support staff, faced with ethical dilemmas, when caring for people with dementia, including people with ID.

While all of these resources are welcome, many grey areas still exist with respect to autonomy in terms of the level of influence it is afforded within the ethical landscape of healthcare, and also the practical application of this moral value in an increasingly embattled health service, where scarcity of resources and value for money predominate. This is particularly relevant in an Irish context where new legalisation relating to capacity and assisted decision making was enacted in 2015 (but not yet commenced) in the form of the Assisted Decision Making (Capacity) Act (ADM).

In addition, formal ratification of the UN Convention on the Rights of People with Disabilities by Ireland in March 2018, will also impact on the rights of individuals with disabilities into the future. The following section addresses the way in which the ethical concept of autonomy, finds expression in the legal concept of capacity and the related requirement of informed consent.

2.6 Exploration of Capacity and Consent

According to Donnelly (2010), the requirement that an individual gives informed consent to medical treatment or research is an ethical and legal condition that gives expression to the right of autonomy. Several Irish national policies have defined the concepts of capacity and consent for the Irish health care setting including *The National Consent Policy* (NCP) developed by the Health Service Executive (HSE, 2017) and guidance documents developed by HIQA (2016), the NMBI (2014) and the IMC (2016).

From a legal perspective, within an Irish context, the ADM (2015), section 3, subsection 1, states that;

> *"a person's capacity shall be assessed on the basis of his or her ability to understand the nature and consequences of a decision to be made by him or her in the context of the available choices at the time the decision is made".*

Both the NCP (2017) and the ADM (2015) assert that all individuals are presumed to have capacity and adopt a functional or decision making approach to capacity. A functional approach to capacity is also consistent with Article 8 of the European Convention on Human Rights (ECHR) and Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD). Such an approach is also identified as best practice, as defined by the Council of Europe recommendation concerning the Legal Protection of Incapable Adults (1999).

2.7 Capacity Assessment

The capacity to make a decision is a pre-condition for the ethical and legal expression of the right of autonomy. Capacity must be assessed in a fair, appropriate and unbiased manner (McCarthy et al. 2011). Assessment of capacity is often a complex procedure and many different standards to establishing capacity have been identified. These include traditional approaches linked to the status of the individuals involved, and the potential outcome of the decision made (LRC, 2005). The ability of the person to understand information provided to them, their ability to make a rational decision, which is consistent with their beliefs have also been considered to be fundamental to establishing capacity (Donnelly, 2010; Yeo et al. 2011).

2.7.1 Status

The status standard according to the LRC (2005), involves making an assessment of an individual's capacity, based on the presence or absence of certain characteristics. Within the context of this approach an individual is deemed to lack capacity based on his or her membership of a specific group or population, such as those with an ID or a mental health issue.

For those with an ID, the impact of this disability varies widely from those with a mild ID who can live independently with minimal support, to those with a profound level of ID who will need significant support to engage in activities of daily living. Under the status standard many individuals, irrespective of their capacity or level of ability would be denied the right to make decisions for themselves based on the fact that they had an ID.

2.7.2 Outcome

The outcome standard according to the LRC (2005), assesses an individual's capacity based on the outcome of their decision. Under this standard, if an individual makes a decision that appears to run contrary to conventional wisdom, the person could be deemed to lack capacity under this standard.

A core tenet of a liberal account of capacity, however, is that the capacity of an individual, should not be based on the outcome of a decision (Donnelly, 2010). The liberal account of capacity identifies each individual as having the right to identify for themselves what it is they want, to come to that decision themselves, and to have that decision respected no matter how bizarre it may seem to others.

For example, in *Wye Valley NHS Trust v B (Rev 1) [2015] EWCOP 60,* a judge ruled in favour of a man who refused to have his foot amputated, in order to prevent the spread of an infection which would claim his life. Although it might appear strange that someone would prefer to lose their life than their foot, in this instance the man's independence was important to him and he was not prepared to forgo it in order to prolong his life. On this view, it must be shown that there is some form of impairment to the person's ability to make a decision; whether the decision itself could be viewed as wise or unwise should be irrelevant. However, Donnelly (2010), suggests that outcomes will continue to play a role in the judicial decision making process where there are issues with testing capacity and where the associated risk to the individual is deemed high. Whether or not this turns out to be the case, post the implementation of the ADM (2015) legislation which seems to lean strongly towards a liberal understanding of capacity assessment, remains to be seen.

2.7.3 Understanding

The ability to understand information, which is of relevance to the decision being made is one of the hallmarks of capacity, reflective of a functional approach to capacity. According to Donnelly (2010), issues arise with limiting an assessment of capacity to just understanding the information provided. While a person may have the capacity to understand the information provided, they may lack the ability to apply it to their own lives or to their specific circumstances.

Other issues such as compulsions, may impact on the ability of a person to apply the information provided to their own lives. For example, cases pertaining to the compulsions associated with anorexia nervosa frequently come before the courts, as those involved grapple with protecting an individual's right to autonomy and mediating the impact of compulsions on decision making capacity.

2.7.4 Rationality

The concept of rationality is expressed in the form of an objectively defensible decision or as a logical process of reasoning. The former would require an individual's capacity to be determined based on an ability to make *"reasonable"* or *"good"* decisions. Issues arise with this premise, as individuals often make decisions that appear reasonable to them, and yet are considered to be totally unreasonable to others. However, the question arises as to who decides what is reasonable (Yeo et al. 2010). With respect to the premise that capacity can be assessed based on an individual's ability to logically and coherently process information, issues also arise. For example, Donnelly (2010) cites *In Re Maida Yetter* (1973), where a woman refused treatment for breast cancer based on its impacts on her career as an actress and her ability to have children. On the surface, these might appear to be logical reasons for refusing treatment, from the perspective of this woman. However, the woman involved did not have a career as an actress and was over 60 years of age, meaning the treatment was unlikely to impact on her ability to have children. Therefore, it could be concluded that despite her capacity to process information logically, she still lacked the capacity to make a decision on treatment.

2.7.5 Consistent/authenticity with an individual's beliefs

A focus on consistency as being reflective of capacity requires that an individual must have the ability to measure the decisions that he/she makes against their own values and views of what is important and not important to them (Donnelly, 2010). However, issues arise as to what degree of authenticity or consistency is required in order to establish capacity. Empirical research has identified that people can change their minds with respect to their will and preferences at end of life. Sometimes, they simply change their minds, or their values or the context of their situation changes leading them to reverse decisions they previously made (Levi and Green, 2010).

To conclude this section, for people with an ID, assessments of capacity have not traditionally been undertaken, in an Irish context. In the main assessments undertaken were focused on establishing the IQ of the individual and their level of ID. (McDermott et al. 2007). There are four distinct levels of ID, which are characterised by Intelligence Quotient according to the ICD-10 Classification (WHO, 1992).

- 50-70 Mild ID
- 35-49 Moderate ID
- 20-34 Severe ID
- <20 Profound ID.

Therefore, within ID specialist services, the focus has been on establishing level of ID, as opposed to level of capacity from a service perspective.

2.8 From Wardship to Assisted Decision Making

Since the inception of the state, approaches to the protection of vulnerable adults have been identified in law. One such approach is Wardship, where an individual is made a Ward of Court under the 19th Century Lunacy Regulation (Ireland) Act, 1871. This law still applies to date and is set to be replaced by the ADM (2015) when fully commenced.

The concept of the Ward of Court system has its origins in the notion of the monarch as the guardian of the people and is paternalistic in its approach (Law Reform Commission, (LRC) 2005). Essentially, a Ward of Court is a person who has been deemed to lack decision making capacity by a court. In such instances, the Court intervenes and, thereafter, has the power to act on behalf of the person, i.e. to make decisions on behalf of the person involved. The impact of being made a Ward of Court, fundamentally changes a person's life, leading to a significant curtailment of their civil liberties and their ability to function as an autonomous individual (O'Neill, 2004). On being made a Ward of Court, the Court is vested with jurisdiction in all matters pertaining to the individual and his or her property (LRC, 2005). While the Court takes into account the views of individuals such as family and friends, there is no obligation under Wardship to identify the will and preferences of the individual. Decisions are made based on the *"best interest"* principle.

A status approach to capacity is also evident in the current Ward of Court system in Ireland according to the LRC (2005). The status approach as discussed in section 2.6.1 lends itself to a broad assessment of the decision making capacity of an individual based on factors such as the person having an ID.

Under this approach, once a person enters Wardship, the person is deemed to lack all decision making capacity, irrespective of the decision being made at the time. In 2005, the LRC determined that the Ward of Court System in Ireland was not fit for purpose given contemporary perspectives of disability. The commission identified that an *"all or nothing"* approach to assessing capacity, did not take into consideration the contextual factors, relating to decision making or address issues such as fluctuating capacity.

The LRC (2005) advocated the adoption of an approach to defining capacity which views people as individuals as opposed to being focused on labels, which are used to define people such as a label of ID. The LRC advocated a move away from the paternalistic approach reflected in Wardship, to a functional assessment of capacity. A commitment to introducing capacity legislation, in keeping with the UN Convention of the Rights of People with Disabilities, was included in the Programme for Government in 2011. The legislation was first introduced in 2013 and was further amended to become the ADM (2015). This new legislation is underpinned by a functional approach to capacity and is explored in the next section of this chapter.

It is envisaged that the act when commenced will replace the Ward of Court system and ensure that the capacity of all existing Wards be reviewed within a three-year period and discharged from Wardship. Those who, on review, are found to lack decision making capacity, will transition to the new system envisaged under the Act.

2.9 Functional Approach to Capacity

A functional approach to capacity is reflected in the legislation of a number of countries including England, Scotland, Germany, Canada, Australia and New Zealand. It is also reflected in the ADM (2015) bringing Irish legislation into line with the Irish constitution, Article 8 of the ECHR's, Article 12 of the CRPD and the Council of Europe (1999). The ADM (2015) will, when enacted, provide a statutory framework for assessing capacity in an Irish context. A functional approach to capacity recognises that the capacity of individuals to make decisions can vary, dependent on the decision to be made and the context in which it is being made. Donnelly (2010), states that whether a person has full capacity, at all times, in all situations should not be the focus of a capacity assessment. Rather, a capacity assessment should establish if the individual involved has the capacity to make a specific decision, at the point in time when the decision is being made.

Capacity can be viewed as a constructed state as, according to McCarthy et al. (2011), it is not simply a characteristic to be assessed but one that can be developed. This speaks to a relational perception of capacity, which requires that efforts are made to enhance a person's capacity and address factors, where possible, which might impede a person's capacity.

Article 12 (2) of the CRPD, clearly states that people with disabilities have legal capacity on an equal basis with other non-disabled citizens and further contends that appropriate supports must be put in place to enable individuals to exercise their legal capacity. The NCP (2017, p.30) also clearly states that it cannot be assumed an individual lacks capacity due to their:

> *"age, disability, appearance, behaviour, medical condition (including ID, mental illness, dementia or scores on tests of cognitive function), their beliefs, their apparent inability to communicate, or the fact that they make a decision that seems unwise to the health and social care professional".*

The NCP (2017) provides guidance on how to provide information and discuss treatment options, the importance of being cognisant of the person's individual circumstances and what information should be provided about interventions, risks and side effects. The NCP (2017, p.21) identifies a number of steps that can be taken to maximise capacity and in support of the guidance provided by the policy, the ADM, (2015) section 3, subsection 3 & 4 states that:

"A person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (whether using simple language, visual aids or any other means). The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him or her from being regarded as having the capacity to make the decision".

The understanding of capacity that underpins the functional approach to its assessment implies that where issues relating to capacity arise, efforts should be made to facilitate individuals to make decisions for themselves (McCarthy et al. 2011). Therefore, health professionals will have to commit time, energy and resources to ensure that people have the capacity to make autonomous decisions. This is of particular importance to people with an ID, where additional supports may need to be put in place to ensure that issues arising relating to communication and cognitive difficulties are adequately addressed. Such supports may include advocates, easy to read materials and augmented or alternative forms of communication such as, sign language, picture exchange systems and assistive technologies (Dalton and Sweeney, 2011).

2.9.1 Supporting those who lack decision making capacity

According to McCarthy et al. (2011) where issues arise with respect to the decision making capacity of an individual it is incumbent on professionals to consult with appropriate experts in the area of capacity such as psychiatrists or psychologists. Legal advice should also be sought as required. Section 3.2 of the ADM (2015), as per the functional test for capacity finds a person lacks capacity if unable:

(a) "to understand the information relevant to the decision;

(b) to retain that information long enough to make a voluntary choice;

(c) to use or weigh that information as part of the process of making the decision; or

(d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology)".

Following on from a capacity assessment, where a person is deemed to lack capacity, it does not follow that their right of autonomy should be dismissed. In fact, according to McCarthy et al. (2011) it is precisely in this situation that any desires, hopes, beliefs and values held by the individual should be affirmed. In addition, if a person is found to lack capacity in a specific situation, it cannot be assumed that the person will continue to lack capacity.

The individual's capacity will need to be reassessed, as situations develop over time. Of significance in terms of differences between the Wardship solution discussed in 2.7 and the ADM (2015), is that under Wardship, there is no obligation to articulate the *"will and preference"* of the Ward, leaving the individual involved without a voice within the system. With the commencement of the ADM (2015), pursuant to subsection 2 to 10, each individual will be assigned an *"intervener"* whose role is to maximise the autonomy of the individual under the Act.

Under the ADM (2015), an intervener is a legally recognised individual whose role is to support the individual involved, referred to as the *"relevant person"*, pursuant to section 2 under the act, to maximise their decision making capacity. The intervener should ensure insofar as practicable, that the individual involved can participate in the decision making process, taking into account the will and preferences, beliefs, values and other factors of relevance to the individual. The intervener can also consider the views of those named by the individual involved, or an individual appointed to support the person when making decisions.

Three forms of decision making supports are available to individuals under the Act; "*Assisted Decision-Making",* (Part 3) *"Co-Decision-Making",* (Part 4) *"Decisions by the court* OR *by a Decision making representative appointed by the court"* (section 38). A designated "*Health Care Representative"* can also be appointed pursuant to section 87 and can support the individual in developing an Advance care Directive.

With respect to assisted decision making, an individual who suspects that their decision making capacity is or may become compromised in the future, can appoint a Decision Making Assistant. The role of the decision making assistant is to support the individual involved, ensuring the individual can access relevant information and supporting the person to make a decision for themselves and to express this decision once made. Within the context of Co-Decision Making, an individual who suspects that their decision making capacity is or may become compromised in the near future, can appoint an individual to jointly make decisions with them. As with the role of the Decision Making Assistant, a Co-Decision Maker is required to ensure the individual has access to the required information to make a decision.

The primary difference between the role of the Decision making Assistant and a Co-Decision Maker is that, only a Co-Decision Maker can actively be involved in making a decision with the individual. It is the role of the Co-Decision Maker to explain the nature of the decision to be made, explore potential alternatives and the likely outcome of such alternative decisions and to identify the will and preference of the individual they are supporting.

A Decision Making Representative is an individual who makes decisions on behalf of an individual who is deemed to lack capacity. In order to appoint a decision making representative, an application must be made before the court. The court will firstly organise an assessment of capacity. If the person lacks capacity, the court will declare that either the person would lack capacity unless a Co-Decision Maker is appointed or the person would lack capacity, even if a Co-Decision Maker were appointed. Where it is determined that the individual lacks decision making capacity even with the assistance of others, a Decision Making Representative is appointed.

The Decision Making Representative can be someone known to the person involved, who is suitable and willing to act on behalf of the person. In the absence of such an individual, the court will request the Director of the Decision Support Service to nominate people from an established panel. The court itself, may also make decisions on behalf of an individual who lacks capacity, in an emergency situation. The court determines the extent of the powers of the decision making representative, who must file a report on the performance of their duties within 12 months of being appointed, and yearly thereafter. Decision Making Representative Orders can be reviewed at any time, at the request of the person subject to the order. These orders will automatically be reviewed on a yearly or three yearly basis by the court, dependent on the individual circumstances of the person involved.

Enduring Powers of Attorney and Advance Healthcare Directives are also given a legislative basis under the act. An Enduring Powers of Attorney is an arrangement where a Donor (i.e. the person who may lack capacity in the future) gives general power to an Attorney (the person who will act on their behalf) in respect of some or all of the person's affairs, such as those relating to the welfare of the individual or in relation to the property of the individual. This agreement only comes into force when the person is deemed to lack capacity.

An Advance Healthcare Directive documents in advance, the will and preferences of a person, with respect to their medical treatment including the refusal of treatment. Under Part 8, section 82 of the ADM (2015), the directive will not apply while the person has decision making capacity. The use of advance healthcare directives also requires that the individual involved had capacity at the point when the Directive was being developed and was also over the age of 18 at the time. Some people with an ID may be unable to develop an Advanced Care Directive, dependent on their cognitive ability, and will need to be included in advance care planning processes in ways other than the creation of Advance Care Directives.

2.10 Promoting the Autonomy and Capacity of People with ID

The introduction of the ADM (2015) and the formal ratification of the UN Convention on the Rights of People with Disabilities by Ireland in March 2018, speaks to a societal, legislative and governmental commitment to promoting the autonomy and capacity of people with an ID. However, the legislative and governmental frameworks in place will only succeed if the requisite time, energy and resources, are provided to promote the autonomy and capacity of people with an ID, when engaging in decision making. This is of particularly importance in specialist ID residential settings as, according to the NIDD, the majority (82%, n=6,201) of those availing of residential services in Ireland have a moderate to severe level of ID (Hourigan et al. 2017).

Advance care planning requires that family members, significant others and health professionals engage in planning conversations, avail of appropriate supports to promote the autonomy and decisions making capacity of the person involved. Specific to supporting people when engaging in advance care planning, it is important that factors relating to diagnosis and prognosis are clarified both for the person with the ID and those supporting them. Johnson (2010, p.142) states that it is imperative to understand the *"stakeholder's terms of reference"* and to check the beliefs, perceptions and assumptions of those involved.

Kingsbury (2010) suggests that advance care planning could be integrated into the already existing person centred planning processes established for people with an ID. Person centred planning is a process widely used in ID specialist services to identify what a person wants from their life and what needs to be done to help the person achieve these goals. This form of planning is reflective of a holistic approach, where the primary focus is on the individual involved (NDA, 2005). It requires that appropriate mechanisms for effective communication are available to all parties involved in planning conversations. Reflective of a relational approach to promoting autonomy and decision making capacity, the importance of relationship building and the inclusion of parents, siblings, other family members and close friends is emphasised. Both person centred planning and advance care planning hold true to the concept of trust, trust that those involved will hold true to the expressed will and preferences of the individuals involved and most importantly will act on these when required.

Kingsbury (2010) also advocates the use of both person centred planning and advance care planning as a mechanism for ensuring the appropriate communication of important information. This author contends that the person centred planning process is the ideal mechanism to bring people together to discuss end-of-life decisions, which professionals have a tendency to avoid and feel uncomfortable about.

Recognising that discussions around end-of-life care can be difficult for people with an ID and their families, Kingsbury (2010) suggests that during the course of the person centred planning process, starting the discussion around decision making early would be advisable, building up to a discussion relating to decisions for end-of-life care. Factors relating to a reluctance to address end-of-life care and engaging in advance care planning on behalf of both families and staff are addressed in Chapter Three of this thesis.

Both Stein and Kerwin (2010) and Kingsbury (2010) state that person centred planning processes identify supporters in an individual's lives who can attest to the individual's capability. It also facilitates the documentation of how the individual communicates, makes decisions and what decisions the person has previously made. Having applied the person planning process to end of life decision-making, Kingsbury (2010) suggests that the emotion attached to the process should not be underestimated. Additional supports may need to be put in place for individuals involved and that the decision making process will not be a once-off conversation but one that will need to be revisited to account for changing circumstances and to develop trust between those involved. The integration of person centred and advance care planning approaches in specialist ID services, could facilitate timely conversations about what the person with an ID, and their family members would want at end of life. Facilitating these conversations as part of an ongoing person centred planning process, would also capture changes in the will and preferences of those involved which can occur over time, and ensure that specialist ID services are prepared to provide end-of-life care.

Conclusion

It is evident that many grey areas exist with respect to autonomy both in terms of the level of influence it is afforded in the ethical landscape of healthcare and its practical application within the healthcare setting. Autonomy is a complex principle which extends beyond the right to reject or indeed the right to accept treatment. Not all individuals will have the ability to make such decisions, and not all individuals may want to. However, even in such situations, respecting individual autonomy and the empowerment of individuals are fundamental principles which should underpin healthcare provision (McCarthy et al. 2011).

At the outset of this chapter, I stated that the principle of autonomy was of specific focus in this study. Within the ID population, many people are completely capable of making independent autonomous decisions. However, reflective of a relational approach to autonomy, some of this population may require, or wish to have, the support of those in their social circle when making decisions. Individuals within the person's social circle, such as family members, friends and staff in specialist ID services, who know the person well, may be instrumental in promoting the autonomy of these individuals by putting in place the requisite supports to enhance an individual's capacity.

This approach is reflected in the functional approach to capacity, which underpins the ADM (2015). It underpins a changing societal perspective of disability, reflecting a discourse which emphasises capacity as opposed to incapacity. Further, it provides a mechanism for people to have a voice, as it is focused on enabling people to participate in decision-making, with support, where required. This contrasts with the approach under the Wardship process which restricts opportunities to make decisions.

The ratification of the UN Convention on the Rights of People with Disabilities, and the future enactment of the ADM (2015), are essential first steps in promoting the autonomy and capacity of people with ID and ensuring that individuals who, heretofore, have been silenced will now have a voice. However, as emphasised in relational approaches to both autonomy and capacity, constructive support from those within the person's social circle are imperative.

This is particularly true for those with more severe forms of ID whose voices may well continue to be silenced unless appropriate supports are put in place to promote their autonomy and decision making capacity. Health professionals working within specialist ID residential settings will need to be particularly cognisant of their role in promoting the autonomy of service users and applying a relational approach to enhancing capacity as the majority of these service users have a severe to profound level of ID and will have specific support needs.

Chapter 3: Review of Empirical Literature of End-of-Life Care and Decision Making Practices

Introduction

The provision of end-of-life care in the ID population is a complex process. Increased life expectancy in Western countries and a more prolonged end-of-life experience (Patja, 2001), coupled with a movement towards empowering people with an ID to make their own decisions, has brought the issue of end-of-life care into sharp focus (Wagemans et al. 2010). Over the past decade, there has been an increased interest in the end-of-life care of people with an ID and how end-of-life decisions are made. This interest is reflected in the growing body of literature relating to this topic.

This literature review is a scoping review which identifies end-of-life research previously undertaken by empirical researchers in the field of ID. Scoping reviews are used to identify existing literature, in relation to a particular topic, irrespective of the methodological approach used (Arskey & O' Malley (2005). A scoping review is considered most appropriate for the purposes of this study, as this form of review determines the extent of the research available and the methodological approaches used.

3.1 Review Process and Data Extraction

Specific to this study, a scoping review was chosen in order to identify, in as comprehensive a manner as possible, empirical research previously undertaken relating to the topic of end-of-life care in the field of ID. A four-step template was used to guide the development of the scoping review (Arskey & O' Malley, 2005; Peters et al. 2015).

1. Identify the research question/objective including the development of specific inclusion/ exclusion criteria.
2. Identify relevant studies through the application of an appropriate search strategy.
3. Extract and chart the data using a data extraction table.
4. Collate, summarise and present the results of the review.

The overarching aim of the scoping review is to establish what is known about end-of-life care supports and decision making practices in ID services. This overarching aim was broken down into the following specific questions.

1. How are end-of-life supports provided to people with an ID?
2. What the preferences and perspectives of people with ID, in relation to end-of-life care?
3. What are the preferences and perspectives of families and staff regarding end-of-life care supports provided to people with an ID?
4. How are decisions made in relation to end-of life care, including the use of advance care planning and advance care directives?

5. Who is involved in making end-of-life decisions in relation to the ID population?

In order to ensure the questions posited in this scoping review were answered, a comprehensive search strategy was developed (see Appendix 1). Four biographical databases were searched commencing in January 2014 including PubMed, CINAHL, Academic Search Complete and Scopus. An audit trail of each database was completed to monitor and document the number of results identified and to ensure transparency. Moreover, search alerts were put in place for each database, to alert me when new research was published in each of the identified databases and were closely monitored across the lifespan of the study.

The identified databases were decided on following consultation with a medical librarian, who also assisted in identifying appropriate search terms. A total of five research terms including synonyms were utilised in the search strategy and are as follows: *"intellectual disability", "end of life", "family", "health professionals"* and *"decision making"* (see Appendix 1 for full list of synonyms used).

Inclusion criteria included studies focused on:

1. Empirical research from 2003-2018 as this timescale captures the major policies changes in relation to service provision for people with an ID and would capture contemporary evidence on end-of life care in the ID population.
2. Focused on end-of-life care specific to the ID population
3. Focused on perspectives and preferences of people with an ID themselves
4. Focused on perspectives of family members
5. Focused on perspectives of ID staff working in specialist ID services
6. Focused on decision making practices on end-of-life care

The exclusion criteria excluded:

1. Non-empirical research such as position papers, editorials and literature reviews
2. Focused on dementia, acquired brain injury or other disabilities in those without an ID
3. Rare genetic disorders, linked to life limiting conditions

Following the application of the inclusion/exclusion criteria the records retrieved from each database were exported to Endnote ™. Following the removal of duplicates and initial screening the available citations were reduced to 264 articles. The majority of excluded studies related to those under the age of 18 and were focused on mortality or life expectancy or the identification of life limiting conditions.

Articles relating to bereavement were also excluded. Following a further review of the studies, 25 were eligible for inclusion. These studies are presented in a data extraction table (see Appendix 2).

3.1.1 Types of evidence

The research designs employed in these 25 studies varied but were predominately qualitative, with 17 studies falling into this category. Qualitative descriptive, phenomenological, ethnographic, grounded theory, nominal group techniques and case studies were used. In the main, individual interviews were used to gather data, using semi-structured or topic guides. Two studies used mixed methods approaches and one study reviewed the files of decedents. The remaining five quantitative studies used questionnaires, the majority of which were specifically developed for the studies undertaken. With respect to geographical location, seven studies were undertaken in the Netherlands, and eight in the UK. Five studies were undertaken in Ireland and two were undertaken in New Zealand. Individual studies were also undertaken in Australia, Denmark and Switzerland (see Appendix 2). A comprehensive discussion of methodological issues will be presented in section 3.7 of this chapter.

The studies reviewed in this chapter were categorised into five central themes, based on the content of each article. These central themes include:

1. Inclusion of people with an Intellectual Disability in End-of-Life Care
2. Families' and Staff's Perspectives on Providing End of Life
3. Communicating about Death, Dying and End of life Care
4. Service Issues in Providing End-of-Life Care
5. End of Life Decisions Making in the Intellectual Disability population

3.2 Inclusion of People with an Intellectual Disability in End-of-Life Care

Increased longevity and changing patterns of morbidity and mortality have caused fundamental changes in the lives of people with an ID, exposing them to a number of significant health conditions and a prolonged period of dying. However, studies which have focused on the experiences and preferences of people with an ID, in relation to end-of-life care are limited. Of the 25 studies identified in this review, only five directly sought the opinions of people with an ID (Tuffrey-Wijne et al.2007; Tuffrey-Wijne et al. 2010., Tuffrey-Wijne et al. 2013; Bekkema et al. 2016; McKenzie et al.2017).

These studies used qualitative approaches and largely focused on those with a mild to moderate level of ID, with the exception of Tuffrey-Wijne et al. (2010) who included five people with a severe to profound level of ID in a sample of 13 people. These studies found that issues arose with talking to people about death and dying in general and having a life limiting diagnosis.

When asked, people wanted to make their end-of-life wishes known and valued the input of their support network at end of life. The themes of being informed of `diagnosis and the importance of support networks were identified from the literature reviewed.

3.2.1 Being informed of diagnosis

Attitudes towards informing people of their diagnosis have evolved over the years for those in the neurotypical population, who are routinely informed of their diagnosis, if they wish. However, several studies have identified that this is not the case for people with an ID who routinely have their diagnosis hidden from them (Tuffrey-Wijne et al. 2007; 2010). Other studies have identified that even when a person is informed, they may not fully understand their diagnosis, an issue which will be addressed in detail in section 3.4.1 of this chapter.

In an ethnographic study, Tuffrey-Wijne et al. (2010) spent over 250 hours with 13 people with an ID who were diagnosed with cancer. This study identified that while 11 of the 13 individuals had been told they had cancer, only two individuals were supported to fully understand their diagnosis and prognosis for the future. In some instances, people were given incomplete information or in the cases of those with more severe forms of disability, they were not given any information. Those with a mild to moderate level of ID could understand their cancer diagnosis when provided with information in an appropriate manner. Difficulties arose where individuals were given conflicting or limited information, or in some instances, no information at all.

When asked if they would want to be informed of their diagnosis, people with an ID expressed a range of views. Tuffrey-Wijne et al. (2013) used a qualitative approach to ascertain the perspectives of people with an ID, and their families and staff, in relation to the disclosure of bad news. Using focus groups, 21 people with an ID were interviewed, along with 88 family carers, ID and medical professionals to identify their perspectives on disclosing bad news.

Focus groups for those with an ID, were conducted using approaches such as story-telling, role play and nominal group techniques, which facilitated the generation and recording of participants' ideas, which were then ranked in order of preference. The interview schedule was built around *"John"* who had a terminal diagnosis, although participants seemed to respond from their own perspectives, as opposed to John's perspective. Responses were mixed; in some instances, people were clear they would want to be informed and would be upset if this information was withheld from them. One respondent stated:

> *"Yes! Because John has a right to know that he is going to die. If I was going to die, and someone kept that sort of information from me, I think I'd be very very upset that somebody was holding that sort of information away from me."* (Tuffrey-Wijne et al. 2013, p. 236)

In other instances, people stated they would not want to be informed; they did not want to talk about dying or, in some instances, were more specific in stating they did not want to talk about cancer.

Other studies (Bekkema et al. 2016) have also identified that when asked, a majority of those interviewed wanted to be informed of their situation. In a previous study Tuffrey-Wijne et al. (2007), again used a four step, structured nominal group technique in focus groups with 33 people. This study sought to ascertain the views of people with an ID on end-of-life care provision. This study found that respondents wanted to be involved in their own care and that it was important to ask people what they wanted and to keep them informed of what was going on.

A further study identified that not only did people with an ID want to be informed of their diagnosis, they also wanted their preferences to be recorded. Bekkema et al. (2016) replicated the approach used by Tuffrey-Wijne et al. (2007) with 14 people with an ID to explore care relationships at end of life. This study, reflecting the findings of both Tuffrey-Wijne et al. (2007) and McKenzie et al. (2017), found that respondents emphasised that not only should the preferences of individuals be ascertained; they should be recorded and honoured.

> *"(about the person's wishes regarding medical treatment) It could be that you can't speak anymore at the end, but if you have it on paper, then your doctor would know and then they wouldn't make a wrong decision afterwards"* (Bekkema et al. 2016, p. 629)

The emphasis that respondents placed on having their wishes respected suggests, that those involved had previously experienced situations where their right to autonomy was not upheld (Bekkema et al. 2016).

McKenzie et al. (2017) undertook semi-structured interviews with four people who had been diagnosed with a life-limiting condition and were engaged in advance care planning. Family members and support staff were also interviewed. This study found that people with an ID wanted to be in control of how decisions were made about their end-of-life care. They wanted to be informed of their diagnosis. They appreciated straight talking and needed information to be provided in an accessible manner.

3.2.2 The importance of support networks

The presence of family and friends, and a support network which could facilitate the person at end of life, was important to people with an ID. They wanted their relationships with families and friends to be supported, so these individuals would be available to support them at end of life (Tuffrey-Wijne et al. 2007). Respondents emphasised that support networks would need to provide a range of supports, including practical and emotional supports, to ensure people were included in their end-of-life care (Bekkema et al. 2016; Tuffrey-Wijne et al. 2007).

While emphasising the need to be consulted, it was stated that if the person could not talk, then those who supported them should be consulted and the person should be carefully observed, where relevant, to identify their preferences (Bekkema et al. 2016). When supporting people with communication deficits, support networks needed to link their previous experiences with the person, to the current situation in which the person found themselves. Connecting with the person and giving the person the space and time to make their wishes and preferences known was also important. These approaches reflect a relational approach to promoting the autonomy of individuals and their inclusion in end-of-life care (Bekkema et al. 2014).

Familiar people such as family and friends were best placed to provide support, to the individual who was dying. Spiritual care was also considered important and respondents felt that this should be provided by pastors, or chaplains or general counsellors. People with an ID also felt it was important to prepare the person for death and support the person and the family to say goodbye. The importance of trusting, caring relationships, with a continuous focus on the wishes of the individual was emphasised, again reflecting a relational approach to autonomy (Bekkema et al. 2016).

To conclude this section, whilst acknowledging the limited research undertaken, it is evident from the research presented here, that people with an ID express different perspectives about being informed of their diagnosis. However, it is clear that people place importance on being in control of how end-of-life care is provided to them and continuing to live their lives while planning the end of their lives. The importance of support networks to people with an ID such as family, friends and paid carers has been identified. People with an ID want their relationships with family members to be supported, so these individuals will be there for them at end of life and to speak on their behalf if necessary.

However, in interpreting these findings it must be acknowledged that in three of the studies, none of those interviewed were unwell or at end of life when interviewed (Bekkema et al. 2016; Tuffrey-Wijne et al. 2007; 2013). Therefore, their perspectives on this topic might change, should they become unwell and require palliative care in the future. Also, the research undertaken to date, has mainly focused on those who have the capacity to effectively communicate their perspectives and preferences. Many people with a severe or profound level of ID do not communicate in conventional ways and may need augmentative forms of communication to facilitate their inclusion in this form of research. Families and health professionals, who know the person well, would also be involved in establishing the will and preferences of these individuals. In addition, all studies in this section are qualitative studies, undertaken across a number of different jurisdictions, limiting the generalisability of the findings.

3.3. Families' and Staff's Perspectives on End of Life

People with an ID, like all individuals, need support at end of life. It is acknowledged that staff and families play a central role in the lives of people with an ID. Nine studies of the 25 identified in the literature focused on families' and staff's perspectives on supporting people at end of life (Li & NJ, 2008; Marlow and Martin 2008; McCarron et al. 2010; Ryan et al. 2011; Wiese et al. 2012; Bekkema et al. 2015; McKenzie et al. 2017; McCarron et al. 2018) A variety of research methods with a predominately qualitative approach were used in these studies. McCarron et al. (2018), used a mixed method approach, while Bekkema et al. (2015) used a retrospective case study approach. Wiese et al. (2012) used grounded theory and Marlow and Martin (2008) used a phenomenological approach.

The remaining five studies used semi structured interviews and topic guides to interview those supporting people at end of life (McKenzie et al. 2017; Ryan et al. 2011; McCarron et al. 2010; Marlow & Martin, 2008; Li & NJ, 2008). These studies found that families and staff were committed to supporting the person with an ID and, in the main, cooperated with each other at end of life. Families and staff were also committed to supporting people to die at home, where possible. Themes relating to a commitment to providing end-of-life care, importance of cooperative relationships and the end-of-life care environment were identified.

3.3.1 Commitment to providing end-of-life care

People with an ID have emphasised the importance of having both family members and staff to support them, when they are dying. Both family members and staff, supporting people with an ID are committed to being there for them and to providing end-of-life care. The majority of staff supporting people with an ID want to provide end-of-life care (McCarron et al. 2018; Todd et al. 2013; Ryan et al. 2011). Ryan et al. (2011) used a qualitative approach to interview 64 members of a multi-disciplinary team supporting people with an ID in one service catchment area in Ireland. All staff felt that end-of-life care was an essential aspect of their professional role and wanted to provide this form of care. Staff felt a strong sense of responsibility and wanted to accompany service users on their final journey. This finding was echoed by Todd et al. (2013), who interviewed 22 staff who had supported 29 people with an ID who died across five ID services.

These staff identified that *"being there"* for the individual involved, was of fundamental importance. However, being there was not simply related to being with the person as they took their last breath. Staff indicated that they supported people across a number of different transition points including; easing the person from living to dying, from being physically present to being absent, and being remembered. While initially dealing with the reality of this was difficult for these staff, they came to view providing end-of-life care as a *"privilege"* which enhanced their commitment to supporting people with an ID.

Families too had to adjust to being in the position of supporting their loved one at end of life. Bekkema et al. (2015) reconstructed twelve cases of people with an ID who had died, by interviewing family members and staff who had supported the individuals involved. When supporting a loved one at end of life, the focus of family members changed from activating the individuals involved and ensuring their inclusion in their communities, to providing comfort care. Families strove to achieve a new balance in the lives of their loved one, as they tried to maintain the functional ability of the person involved in the face of complex and uncertain situations. Marlow and Martin, (2008, p.345) use the metaphor of embarking on *"a voyage of grief and discovery"* to explain the experiences of the families involved. Both families and staff sought to maintain the person at the centre of the caring process.

Family members, according to Bekkema et al. (2015), stated that paying attention to the person who is dying, and what they are trying to communicate is essential. It allowed family members to build a shared understanding of what the person was trying to communicate. Families felt a strong moral obligation when making decisions and wanted to promote the autonomy of their loved one. Bekkema et al. (2014) suggest that by paying attention to the information needs of the individual involved, connecting with the individual, recognising end-of-life care needs, giving the person space to identify their preferences and discussing dilemmas, families could promote the autonomy of people with an ID at end of life.

Staff too emphasised the importance of maintaining their focus on the individual. Within an Irish context, McCarron et al. (2010) undertook a qualitative study, using focus groups to explore 56 staff's perspectives of essential prerequisites of end-of-life care. This study found that keeping the person with the ID at the centre of care was a guiding principle in the delivery of care. Maintaining relationships with family members and staff who knew the person well was considered important. Respondents spoke of their pride in providing good quality care and doing *"ordinary"* or basic things well. Promoting the psychosocial needs of the individual and helping them to engage in activities they previously enjoyed, was also considered important to their ongoing care. Respondents felt that attending to someone's spiritual care was important, but many felt ill-equipped to do so.

3.3.2 Importance of cooperative relationships

Research in this area has identified the importance of cooperative relationships between families and staff when supporting people at end of life (Bekkema et al. 2015). Families required the cooperation of support staff and other health professionals, such as doctors, when their loved one was dying. This led to an intensified relationship between families and staff. Families visited more often, became involved in the care process and, in some instances, jointly provided care. Some families also coordinated their activities with staff, for the purpose of ensuring there was someone familiar to comfort the person. Some relatives were full of praise for these staff and the support they provided.

In other instances, differences arose as to what good end-of-life care entailed and families felt staff were infringing on the family's privacy and their rights as representatives of the individual (Bekkema et al. 2015). McKenzie et al. (2017), also identified the importance of cooperation and collaboration between families and support staff. In this study, close collaboration between support staff and families was felt to be particularly important in order to identify, in advance, the possible future requirements of the individual and the resources available to meet them. The authors state that this collaborative relationship is essential in ensuring the advance care plans of people with an ID are implemented.

The intensified relationship between staff and families at end of life meant that, for some families, there came a growing realisation that their loved one had *"two families"*, the person's family and care staff (Bekkema et al. 2015). McCarron et al. (2018) also found that staff supporting people with an ID in residential services formed bonds with the person at end of life, similar to their biological family. Similarly, Todd et al. (2013), also found that staff saw themselves as an extension of the individual's family. However, where families had not been consistently involved in the person's life for many years, tensions could be raised.

> *"Just before he died, his mother and father came for the first time in 12 years. I'd known him for 20 years. So who was his family?"* (Todd et al. 2013, p. 224)

While Marlow and Martin (2008) did not find that families viewed support staff as a second family, it was evident that families did recognise that a partnership existed between them, in supporting the dying person. Families expressed concern about the impact of providing end-of-life care on staff, again reflecting the close relationship between support staff and families. That these families did not view staff as a second family, may be explained by the fact that none of the individuals involved were cared for in large scale residential settings where a consistent relationship with staff might have been built over a number of years. They were cared for across a number of disparate services and also within their family homes.

Providing end-of-life care had an emotional impact on families and staff, with both parties experiencing a broad range of emotions at end of life (Bekkema et al. 2015; Marlow and Martin, 2008). Marlow and Martin, (2008) interviewed six family members in a phenomenological qualitative study. When interviewed, family members stated they had experienced extreme mental, physical, social and spiritual pressure and had to *"dig deep"* to manage their situation and support their loved one at end of life, as evidenced by this quote from one respondent.

> *"I still find it hard to deal with…seeing Simon die. That's a part that I haven't really got over yet…you get flashbacks…I haven't come to terms with that…it's just really painful. (Sandra)"* Marlow and Martin, (2008, p. 347).

Bekkema et al. (2015) found that staff had to manage their emotional and professional responses at end of life. For some staff, this became a struggle because of the intensity of the end-of-life experience.

> *"We always had a special bond. I was really fond of Joe. He was really one of my special clients. (in tears) In the team, we decided to care for him ourselves. He wanted to be with us. It felt like family. Caring for him at the end of his life was hard but rewarding. I tried to keep in mind that he was my client, to help me cope"* (Bekkema et al. 2015, p.6).

Many staff found it difficult to provide end-of-life care and maintain emotional distance. Staff found that reflecting on their experiences was important in finding a balance between providing empathetic, person centred care, without becoming overly involved emotionally. However, Ryan et al. (2011) suggest that staff are not offered enough supports when the individuals in their care are at end of life. These authors suggest that the depth of this relationship, between staff and individuals with an ID is not understood at an organisational level.

3.3.3 End-of-life care environment

The issue of where people with an ID receive end-of-life care has been identified as of importance. While many families have indicated that they want their loved one to die at *"home"* (McCarron et al. 2018) ID staff, across jurisdictions have expressed strong views about where care should be provided (Wiese et al. 2012; Todd et al. 2013; McCarron et al. 2010). Wiese et al. (2012), undertook a grounded theory study to establish the issues facing 33 direct care and management staff supporting people with an ID in community living services in Australia. These authors found that staff were committed to providing end-of-life care, where the person wanted to be cared for. Participants felt that end-of-life care should be offered in the place most familiar to the individual, and this was interpreted as home. This finding is echoed by McCarron et al. (2018) who found that people at end of life, were best cared for in familiar environments, with familiar people, providing person centred care using coordinated multidisciplinary approaches.

In a previous study, McCarron et al. (2010) found that staff felt it was imperative that a peaceful environment be provided at end of life, particularly for those with an ID and end stage dementia. For some, this involved the development of specialist units to support such individuals, for others this involved maintaining them in their own home.

This finding was also reflected in a study by Li and Nj, (2008) who employed a qualitative, descriptive case study approach to identify the end-of-life experiences of five learning disability nurses in England. The respondents in this study, strongly indicated that people with ID should die in familiar surroundings.

> *"[T]his is where she is happiest and unless there was an emergency […] this is where she would die"* (Li & Nj, 2008, p.952)

However, despite the fact that dying at home or *"in place",* was viewed as the appropriate place for the person to end their days, not all deaths in residential settings were peaceful. According to Todd et al. (2013), for some staff, some deaths could appear difficult and prolonged, depending on staff's level of competence to provide end-of-life care. In some instances, staff found it difficult to deal with the physical aspects of death and found the situation challenging, causing them to review their commitment to keeping the person at home (Todd et al. 2013).

While staff were committed to supporting the person at home, they did not believe that this should be done at any cost (Wiese et al. 2013). A number of studies identified practical issues that needed to be addressed in order to provide good quality end-of-life care (Wiese et al. 2012., McCarron et al. 2018). McCarron et al. (2018) undertook individual interviews using the 'The Views of Informal Carers-Evaluation of Services Short Form' (VOICES-SF). The questionnaire consists of 58 items, with closed questions providing the quantitative data for the study. The VOICES questionnaire was developed by Addington-Hall and McCarthy (1995) to capture information on quality of care, service use and unmet needs as people approach end of life and had not previously been used with an ID population. Factors such as the availability of medical expertise, working within one's scope of practice and the availability of equipment, were all seen to impact on the ability of staff to support people at end of life, in their own homes. In some situations, staff struggled to provide optimal end-of-life care and this issue seemed to be heightened where the person had a number of co-morbid health conditions such as dementia (McCarron et al, 2010). In such instances, staff could become overwhelmed.

Where ID organisations could not support people when they were dying, they had to be transferred to hospital (McCarron et al. 2018). Both staff and families said they found it difficult when the person had to be moved. In some instances, ID staff viewed hospital deaths as *"failures"* as they felt that they should be able to provide the necessary supports for individuals in ID services, where the death was expected (Todd et al. 2013). In these situations, if the necessary supports were not available and the person had to be transferred to hospital, then ID staff felt they had failed the individual involved.

This perspective was also identified by Ryan et al. (2011) who found that staff felt guilty and experienced a sense of failure if they did not manage to bring someone home from hospital. Some staff considered deaths in hospital ironic, since the person ended up dying in an institution, while the focus of disability services is on moving people from institutions, to community living (Todd et al. 2013). This sense of failure was compounded by the fact that in some instances, ID staff were unhappy with the level of support provided to people with an ID in acute hospital settings (McCarron et al. 2010). These staff expressed frustration that decisions were made without consultation or communication with ID service staff. These ID staff felt that acute hospital settings were poorly equipped to make decisions specific to people with an ID. One respondent in this study stated:

> *"You usually go to a different doctor each time, you don't build up a relationship, you are usually with a very junior member of staff who isn't going to make […] to have that experience to make these difficult decisions."* (McCarron et al, 2010, p. 147)

Despite this, the research indicates that not all hospital deaths were seen as failures (Todd et al. 2013). If hospital staff were perceived to value the person with an ID and to value the input of staff supporting them, then deaths in such settings were viewed positively by staff. Reflective of the ongoing commitment of staff to provide end-of-life care, a hospital death involved staff *"rallying round"* sometimes providing unpaid care when the person was in hospital. Staff felt that just because the person had been removed from their home, they should not be abandoned. Staff spoke of the importance of placing the person at the centre of a caring community (McCarron et al. 2018) and being eased from life to death (Todd et al. 2013). Where this did not occur, and staff were prevented from *"being there"*, staff experienced a sense of failure, both of their own care standards and the care systems in which they operated. Similar to Todd et al. (2013), Wiese et al. (2012) also found that staff in community disability services remained committed to supporting the person at end of life, even when the person was transferred to hospital.

This continuation of care for the individual was linked to the commitment of staff and a desire to maintain the relationship with the individual involved. In some instances, rosters were altered to incorporate regular visits to the hospital by staff; in other instances, such visits were made in the staff's own personal time. On some occasions, staffing situations in community facilities had to be reorganised in order to provide full time care for the individual by staff from the community ID services in the hospital setting.

To conclude this section, there are a limited number of studies available relating to families and staff's perspectives of end-of-life care. The majority of these are qualitative. Although other approaches such as mixed methods have been used, even in these studies, qualitative approaches predominate.

These studies have focused on disparate aspects of the role of families, making comparison of these studies difficult and limiting the generalizability of findings. With respect to studies relating to families, the majority focused on those recently deceased. However, Marlow and Martin (2008), interviewed family members who had been bereaved from between six months to seventeen years. Therefore, issues such as the impact of the grieving process immediately after the death of the individual and respondent recall, might have impacted this study.

Studies relating to staff focused on a variety of professionals across a number of services. Although the majority of studies are qualitative, large numbers of people were interviewed in some studies. For example, Ryan et al. (2011) and McCarron et al. (2018) interviewed 64 and 56 people respectively. This improves the generalizability of the findings of these studies.

Despite the afore mentioned methodological issues, it is evident that both families and staff are committed to supporting people with an ID at end of life. Families valued the cooperation and support of staff in supporting their loved ones. In some instances, both families and staff viewed staff as an extension of the family unit. However, in other instances, issues arose and relationships between families and staff could break down. Providing end-of-life care took an emotional toll on both families and staff. Staff in some services felt that senior management did not fully understand or appreciate the nature of the relationship between families, staff and the person at end of life. In these instances, staff felt unsupported.

Both families and ID staff, were committed to support people in familiar environments and staff in particular were left with a strong sense of guilt and failure if unable to maintain people in their home. If the person was transferred to hospital, in some instances, staff were prepared to provide support in their own personal time. ID staff's perspectives on maintaining the individual at home changed if the person could not be appropriately supported at end of life, and the issue of providing good end-of-life care took precedence over the environment in which care occurred.

3.4 Communicating about Death, Dying and End of Life

A total of 11 studies, from the 24 studies reviewed, focused on issues relating to informing the person of their diagnosis (Tuffrey-Wijne et al. 2008; Tuffrey-Wijne et al.2010; Ryan et al. 2010; Wagemans et al. 2010; Wiese et al. 2012; Mortan -Nance and Schafer, 2012; Tuffrey-Wijne et al. 2013; Wagemans et al. (2013a); Bekkema et al. 2014; Tuffrey-Wijne & Rose 2017; McCarron et al. 2018). Most of these studies were qualitative although McCarron et al. (2018) used mixed method approaches.

Tuffrey-Wijne et al. (2008) conducted a quantitative study, using a questionnaire specifically developed for the study. This study also focused on topics explored in qualitative studies and the findings of this study were reflective of the findings from qualitative studies. The questionnaire did allow sections for qualitative comments also, and 192 of the 503 respondents made comments in this section.

The issue of non-disclosure has been referred to in the literature relating to end-of life care. Tuffrey-Wijne et al. (2013) found that medical and nursing staff in hospitals and hospices were far clearer and more confident about reasons for non-disclosure. These professionals asserted that cases should be looked at individually and that a capacity assessment should be done to identify the level of comprehension of the individual involved (Tuffrey-Wijne et al. 2013). The concept of time, was also a factor, as explaining what would happen in the future can be difficult if a person cannot distinguish between today, tomorrow or next week. These authors indicate that the person with an ID needs to be involved - their life experiences and their coping ability should all inform the decision to disclose or not. Most importantly, the person's individual perspective relating to disclosure should also be factored in.

The research in this area has found that few people with an ID are made aware of their diagnosis. In an ethnographic study of 13 people with an ID and a cancer diagnosis, Tuffrey-Wijne et al. (2010) found only two individuals who were fully informed of their diagnosis and future prognosis. This finding is also reflected in the findings of Wiese et al. (2012) who found that although staff believed people with an ID should be involved in conversations about death and dying, this opinion did not translate into practice. Ryan et al. (2010) also identified that while staff recognized the impact of death and dying on people with an ID, again, nothing was done in practice, for example, to prepare people for the impending deaths of their peers. Supports were provided after people had died, suggesting that staff were more comfortable having conversations about death and dying after a person had died, rather than preparing those involved for the death, beforehand. Several reasons for the disclosure or non-disclosure of bad news have been identified in the available literature. These include issues in relation to capacity and communication and the ability of staff to engage in conversations about end-of life issues.

3.4.1 Capacity and communication

One of the reasons proffered by healthcare professionals for not engaging in conversations about death, dying and end of life, is the fact that the person has an ID and staff had issues relating to their level of capacity.

A study undertaken by Bekkema et al. (2014 a) identified that 69.5% of the 248 GPs, ID physicians and care staff surveyed believed that people with an ID should always be informed of an intervention which the authors felt was low, given the legal requirement in the Netherlands to inform the person of such interventions.

Despite this stated belief, only 29.8% of people with a mild to moderate level of ID and 2.9% of those with a severe level of ID were consulted in relation to their treatment. The findings of this study suggest that level of ID and capacity issues impact on communication about end-of-life issues. People with more severe levels of ID were not informed. However other studies (Wagemans et al. 2010) have identified that people with an ID are not informed they are dying irrespective of their level of ID.

Wagemans et al. (2010) also referenced the issue of capacity as an impediment to the inclusion of people with an ID in their end-of-life care. These authors undertook a retrospective review of the files of seven people with an ID who had died and found that doctors automatically assumed that those involved would not have the capacity to make decisions based on the fact they had an ID. This perspective reflects a status approach to assessing capacity. These authors found that communication between the doctor and the person with ID, occurred in only 38% of cases. In a further study, Wagemans et al. (2013a) identified that all nine physicians interviewed in their study expressed a belief that the person lacked the capacity to be part of the decision making process, irrespective of the level of ID of the person involved. This was also found to be the case by McCarron et al. (2018) who found that staff did not feel that the person with ID could understand the concept of death, and, therefore, did not inform the person of their situation. In a previous study of patient representatives undertaken by Wagemans et al. (2013) it was also identified that family members did not believe that their loved one had the capacity to make choices about whether to have chemotherapy or not, irrespective of the level of ID of the person. In some instances, this was because the person was very ill by the time it came to make decisions.

How best to communicate with the individual involved was also an issue in informing people with an ID about their diagnosis. In a study in the Netherlands, Bekkema et al. (2014), explored factors which impeded the efforts of support staff and families to promote the autonomy of people with an ID. Caregivers were usually aware of the prognosis of the individual involved before the individual was, and issues arose as to how best communicate the diagnosis, how to ascertain what the person would want to know, and how much information would the person be able to deal with.

Those involved thought the person had the right to know. However, in cases where the person was very ill or had a severe ID, it was more difficult to identify their information requirements. While it was easier to communicate about illness with those with a mild, as opposed to a severe level of ID, it did not always follow that people with a mild ID were given this information.

This finding was also reported by Tuffrey-Wijne & Rose (2017) who interviewed 20 social care workers who had supported people with an ID at end of life. Those staff who were open to communicating about death and dying would find a way to effectively engage with individuals, irrespective of their level of ID. Staff who wished to avoid these conversations would also do so, irrespective of the level of ID of the person, in some instances using euphemisms or couching their words, making it difficult for the person involved to fully understand their situation.

3.4.2 Engaging in conversations about end of life

Other issues, extrinsic to the person with an ID, have been found to impact on disclosure. The ability of those supporting people at end of life to engage in conversations about death and dying has received some scrutiny. In some instances, staff did not think it was their job to hold these conversations. Whether staff saw communicating about end-of-life care as part of their role, was linked to organisational culture according to Tuffrey-Wijne & Rose (2017). These authors found that junior staff tended not to perceive engaging in these forms of conversations as part of their role. However, in services where managers were positive role models and talked to their staff and people with ID about death and dying, then junior staff were more likely to engage in these conversations. The provision of clear staff supports structures and guidance around death and dying also promoted engagement in conversations about end of life.

Breaking bad news was a significant issue as many professionals found it difficult and lacked the tools and skills and confidence to have such conversations. Mortan-Nance and Schafer, (2012) in a phenomenological qualitative study, used open-ended questions to interview three learning disability and three district nurses. Issues in relation to communicating with people with an ID featured strongly in this study, as respondents' approach to communicating impacted their ability to understand people with ID. Respondents were concerned about their ability to exchange important information with people with an ID. The majority of those interviewed stated that they lacked the skills and the tools to explain the concept of dying. However, Todd et al. (2013) found that in some instances, even if staff had identified ways to inform the person involved in a manner which they could understand, the person was still not always informed. This would suggest that more than one factor impacted on whether a person was informed of their diagnosis or not.

Mortan -Nance and Schafer (2012), found that respondents were uncomfortable about breaking bad news to those involved.

> *"I wouldn't know where to begin. It is very hard to say to somebody you may not survive this [...] but someone with a learning disability, I mean how would you couch it?"* (District nurse 1). Mortan -Nance and Schafer, (2012, p.45)

It was also identified by Bekkema et al. (2014) that those facilitating these discussions should be comfortable about discussing the issues of death and dying and be able to speak openly and honestly about the topic. Situations where facilitators were not open and honest seemed to develop from a lack of knowledge on a topic or where individuals were given conflicting advice. In some instances, the individual involved was presented with a *'hypothetical situation'* instead of being openly informed about his or her situation, which according to Bekkema et al. had the potential to cause confusion. This situation usually arose with respect to legal issues which may be one of the reasons why issues such as making a will and enduring powers of attorney had not been explored for those involved (Bekkema et al. 2014).

Issues in relation to the level of knowledge of the person breaking the bad news were also identified by Tuffrey-Wijne et al. (2013, p.237), where those involved did not understand the diagnosis themselves.

> *"Somebody became acutely ill and was asking me, "Am I going to die?" And I wasn't able to answer that question, because I didn't fully understand the prognosis".*

Issues relating to emotional distress also impacted on whether the person was made aware of their situation or not. Tuffrey-Wijne et al. (2013) found that, in some instances, the person breaking the bad news could not do so as they found the situation too overwhelming. While this issue predominately affected family members, staff in ID services also expressed this view. However, medical staff did not identify this as an issue. Similarly, people with an ID were not informed they were at end of life, as staff sought to avoid emotional suffering on the part of the individual involved. Therefore, dying occurred in secret, with staff becoming *"secret escorts"* accompanying the individual across the trajectory from life to death (Todd et al. 2013).

> *"We never told Stephen. He understood that there was a problem with his head. We told him that he had a swelling and that the doctor would give him a small operation to bring it down. He was afraid of dying. We spoke to his sister and she didn't want him to know. He's suffered all his life so why make it worse now"* (Todd et al. 2013, p.223).

In some instances, staff indicated that they found it hard to keep up the pretence. Nevertheless, they did not tell the person involved they were dying. In some instances, staff did not inform the person, even when it went against their own moral principles.

One study undertaken in Australia identified that staff had strong views that people with an ID should be told of their diagnosis, based on their own ethical values (Wiese et al. 2012). These ethical values were reflected in the use of terms such as *"respect, "dignity" and "choice".* In some instances, these values brought staff into conflict with other professionals or family members who did not want their loved one informed of their diagnosis. In the majority of cases, the wishes of the family were given precedence and staff were compelled to maintain the pretence, going against their own moral beliefs.

Families and staff believed not fully informing or talking about the illness or declining health of the individual spared them emotional distress. Tuffrey-Wijne et al. (2010) found that this was not always the case. In two of the 13 cases in this ethnographic study, the individuals involved eventually figured out that they were seriously ill. In both cases, instead of becoming distressed and upset, both individuals accepted their diagnosis with stoicism, and were calm and peaceful when they died.

To conclude, this section, several studies have been undertaken which focus on conversations about death, dying and end-of-life care. This research has focused on discussing issues relating to death and dying on a broad level, down to the specifics of discussing end-of-life care with an individual who is palliative or at end of life.

Although most of these studies are qualitative, large numbers of people were interviewed in some studies. For example, Ryan et al (2011) and McCarron et al. (2018) interviewed 64 and 56 people respectively. Tuffrey-Wijne et al. (2013) interviewed 109 people. This improves the generalizability of the findings of these studies. However, the studies have been undertaken across multiple jurisdictions and a variety of services. A broad range of professionals with a variety of skills were also interviewed in these studies, along with people with an ID and family members to a lesser extent. These factors impact on the generalizability of the findings of these studies.

Despite these methodological issues, common themes have been identified from the literature. While health professionals state that they believe people should be informed if they are ill or are at end of life, the majority of people with an ID are never informed that this is the case. Staff and families grapple with their own emotional responses to breaking bad news, a lack of communication skills, capacity issues and differing perspectives as to whether the person should be informed or not.

In some instances, the person was not informed as family members did not want their loved one to know. While those supporting people with an ID most frequently cited capacity and communication issues as a reason for not informing the person, it is also evident that factors relating to the attitudes and skills of those supporting these individual significantly impact on whether a diagnosis is disclosed or not.

3.5 Service Issues in Providing End-of-Life Care

It is evident that those supporting people with an ID at end of life were committed to doing so However, five of the 25 studies presented here have identified that issues have arisen as to how prepared health professionals and organisations are to provide this form of care. Three studies were quantitative, (Bailey et al. 2016; Tuffrey-Wijne et al. 2008; McCarron et al. 2018). Ryan et al. (2010) used mixed methods and Wiese et al. (2012) conducted a grounded theory study. These studies have found that issues arise in relation to the knowledge and experience of staff and coordination and communication within services. These issues impacted on the preparedness of individuals and organisations to promote end-of-life care.

3.5.1 Knowledge and experience

Health professionals support people with an ID at end of life across diverse settings and, in some instances, these individuals lack the knowledge, experience and skills required to support them. For example, staff in ID services predominately lack experience in providing palliative care (Wiese et al. 2012). Conversely, palliative care staff lack experience in supporting people with an ID (Ryan et al, 2011). This impacts on the confidence of all parties called on to support those with an ID.

Wiese et al. (2012) found that ID staff supporting people in community settings had varying levels of knowledge and experience of providing end-of-life care across a continuum from total naiveté to intimate knowledge of end-of-life care. Some staff providing support to people at end of life were fearful of their lack of experience and ability to provide this form of care. This lack of knowledge and experience could heighten the anxiety and insecurity of staff in these situations.

Conversely, palliative care staff have limited experience of providing care to people with an ID on a continuous basis (Tuffrey-Wijne et al. 2008., Bailey et al. 2014., Ryan et al. 2010). Ryan et al. (2010) used a mixed methods approach to identify the experience, confidence, and attitudes of 91 staff supporting people with an ID in one health service area. This study found that that although 59.3% (n=57) of palliative care staff had provided end-of-life care to a person with an ID, 66% had not cared for a person with an ID at end of life in the previous year. A total of 35.1% (n = 33) of respondents had cared for a person with ID and palliative care/end-of-life care needs in the last three years.

In an exploratory descriptive study, Bailey et al. (2016) used a cross-sectional survey questionnaire with open and closed questions to explore the experiences of 94 community based palliative care and public health nurses, of whom 33 had received a referral regarding a person with an ID in the previous three years. This study found that 72.7% (n = 24) had dealt with more than two cases, 18.2% (n = 6) had dealt with between three to five cases and 9.1% (n = 3) had dealt with more than nine cases. These findings suggest that palliative care staff have limited interactions with people with an ID and according to Ryan et al. (2010) lack confidence because of their lack of knowledge and experience. These nurses described caring for someone with an ID as *"different"* and *"difficult"* and felt that people with an ID had specific needs which these staff were unsure they could meet.

Both ID staff and palliative care nurses indicated they lacked the skills to support people with an ID at end-of-life. Lack of knowledge and skills was identified by McCarron et al. (2018) who found that ID staff could not *"join the dots"* with respect to providing end-of-life care. Bekkema et al. (2015) reported that it could be challenging for ID staff to assess pain, anxiety and other determinants of distress in people with an ID, a finding with which McCarron et al. (2018) concur.

Tuffrey-Wijne et al. (2008) administered 1,400 questionnaires to palliative care professionals across a variety of settings with a response rate of 57% (n=543). This study found that 43% (n=151) of palliative care nurses stated they did not think they had enough skills to support people with an ID. This lack of skills impacted on the management of symptoms at end-of-life, as palliative care nurses found assessment difficult with 43% encountering difficulties in assessing pain and 47% (n=164) of palliative care nurses finding it difficult to assess other symptoms in people with an ID.

Communicating with individuals at end of life was difficult both for palliative care nurses and ID staff Over 73% (n=257) of palliative care nurses found it difficult to know what to do when the person could not fully understand their illness and treatment, and 42% (n=146) found it difficult to understand the person's method of communicating (Tuffrey-Wijne et al. 2008). ID staff too experienced a decrease in confidence when communicating with and managing pain and other symptoms in people with ID at end of life in comparison to supporting those who were not at end of life (Ryan et al. 2010). In managing these communication issues, Bekkema et al. (2015) found that ID staff had identified that small changes in behaviour or other small physical responses can be important indicators of symptoms in people with an ID.

Two values emerged in the process of addressing communication issues; attentiveness to the person's signals and what they were trying to communicate, and, openness to cooperation in order to build a shared understanding of what the person was trying to communicate (Bekkema et al. 2015).

Bailey et al. (2016) also found that palliative care staff felt that people with an ID could be very frightened due to a lack of understanding of what was going on, and a change in environment. Caring for these individuals, within a hospice or hospital setting was time consuming. Staff had to rely on families and staff from ID services to try to ascertain the person's emotional state and to address queries in relation capacity and consent.

A lack of training was also an issue for both professional groups. Ryan et al. (2010) found that ID staff felt their training in end-of-life care was inadequate and none of them had encountered specialist palliative care staff while training. ID staff felt limited by their lack of knowledge, as they did not know what palliative care services were available or what to ask for. With respect to palliative care nurses, two thirds (61%) of palliative care nurses had not received any training in supporting people with an ID according to Tuffrey-Wijne et al. (2008), and only 27% of respondents knew where to contact ID professionals for support.

3.5.2 Coordination of services at end of life

Issues were identified according to Wiese et al. (2012) and McCarron et al. (2018) in relation to effective coordination and communication both within and between services. This impacted on the preparedness of organisations to provide end-of-life care to people with an ID. In some instances, issues arose at the level of individual staff, in other instances, issues arose at service level.

Poor communication and lack of collaboration between individual health professionals was found to impact on the provision of end-of-life care. Morton-Stance and Schafer (2012), found that nurses reported that their experience of providing end-of-life care for people with an ID was impacted by the attitudes of other professionals and carers. Where conflict arose due to individual attitudes, it inhibited collaborative working between ID and community nurses. A lack of understanding of other people's roles and poor sharing of information was also problematic. Overall, these nurses reported that communication difficulties between professionals was seen to affect the quality of care provided to people with an ID.

Coordination and communication between ID and palliative care services was identified as paramount in the provision of end-of-life care for people with an ID by both Ryan et al. (2010) and Bailey et al. (2014). Effective coordination and communication were seen to impact at organisational level, as found by Bailey et al. (2014). This study found that effective communication had the potential to foster interagency collaboration both within and between services.

On a cautionary note, while Ryan et al. (2010) also found that both ID and palliative care staff stated that working partnerships were important, the desire to cooperate was not enough to ensure that this happened.

This study found that palliative care staff were less proactive when dealing with people with ID and relied on ID staff to support these individuals. ID staff stated there was a tradition within ID services to deal with issues *"in house"* and not to seek support from outside agencies such as community palliative care services or hospices.

This lack of coordination and communication between services appears to impact on the referral of people with ID to palliative care services. Tuffrey-Wijne et al. (2007, 2008), suggest that people with an ID are not referred to palliative care services as often as they might. From an Irish perspective, Bailey et al. (2014) identified a 1.2 % prevalence rate of referrals to palliative care services for those with an ID in comparison to the 2.5% prevalence rate for the neurotypical population. The findings suggest that people with an ID are not routinely referred to palliative care services in Ireland. This low rate of referrals is of concern, since those with an ID who are referred to palliative care services need significant support. Tuffrey-Wijne et al. (2008) found that when people with an ID were referred to palliative care services, 71% (n=247) required support with symptom control, 36% (n=127) required terminal care and 28% (n=98) were referred as their family needed support. In addition, 24% (n=83) of patients needed psychological support, 22%(n=77) required respite care, and 11% (n=40) required day care. Bailey et al. (2014) also identified that reasons for referral to palliative care services included providing support for both staff and family members, as well as for the person at end of life. Given the support needs required by people with ID, their families and the staff supporting them, it is of concern that they are not routinely referred to palliative care services for support.

To conclude this section, the majority of studies relating to the preparedness of staff and services to provide end-of-life care were quantitative in nature. Sample sizes varied from 543 to 97 (Tuffrey-Wijne et al. 2008; Bailey et al. 2016). A wide range of professionals were identified across diverse services, including specialist ID and palliative care services. These factors impact on the generalizability of these findings. Despite these methodological issues it is evident that being committed to providing end-of-life care is not enough to make good end-of-life care happen. Irrespective of their professional background, all staff expressed reservations about their level of knowledge and skills when supporting someone with an ID at end of life.

This, from a positive perspective, led to professionals such as ID and palliative care nurses working collaboratively together, in some instances. However, from a negative perspective, it impacted on the accessibility of services for people with an ID, in some cases. Moreover, while collaboration often occurred between individual staff, it did not occur at organisational level. This led to reactive as opposed to proactive approaches to service provision, impacting on the quality of end-of life care provided to people with an ID.

3.6 End-of-Life Decision Making in the Intellectual Disability Population

Of the 25 studies included in the review, eight focused on end-of-life decisions in relation to the ID population. Of these, four used a qualitative approach, (Bekkema et al. 2014 a; Wagemans et al. 2013; 2013 a; McKenzie et al. 2017) and four used a quantitative approach (Witchki & Hallich, 2017; Wagemans et al. 2010; Bekkema et al. 2014 a; D'Haene et al. 2010). Several common themes were found in the literature including the prevalence and forms of end-of-life decisions in relation to the ID population, making end-of-life decisions and who is involved in making these decisions.

3.6.1 Prevalence and form of end-of-life decisions in the Intellectual Disability population

End-of-life decisions have been explored in a number of studies undertaken in the Netherlands and Switzerland (Witchki & Hallich, 2017; Bekkema et al. 2014 a; Wagemans et al. 2010). These studies used qualitative approaches to explore the prevalence and form of end-of-life decisions in the ID population. Wagemans et al. (2010) undertook a retrospective review of the case files of 47 people who had died. This study found that end-of-life decisions encompassed withholding NG feeding (n=8); withholding therapy (n=7); DNR (n=25) and decisions relating to pain relief symptom management (n=12). These findings are reflected in the findings of Witchki & Hallich (2017), who undertook a cross-sectional survey of directors of residential homes in German-Italian and French speaking Switzerland. Information was provided on 233 people from eight residential homes. Of these 97 had an ID, 59 had an ID and some other form of disability and 77 people had sensory, physical or psychological issues. Witchki & Hallich (2017), identified end-of-life decisions in 74% of cases (n=164). Pain and symptom control was provided to 58% (n=139) of individuals; life prolonging treatment was withdrawn in 39% (n=91) of cases and 14% (n=33) of people received palliative sedation. A decision to discontinue atypical nutrition was taken in 27% (n=64) of cases.

Bekkema et al. (2014a) found that potentially burdensome interventions were discussed in 58% of cases. These decisions included whether to commence or discontinue interventions such as pain medication via infusion pump or NG feeding. Withdrawal of artificial nutrition or respiration occurred in 27.5% of cases. Three cases of assisted suicide involving those with an ID were identified by Witchki & Hallich (2017), and these decisions were made by the doctors and nurses involved in their care. Conversely Wagemans et al. (2010) found no instances of euthanasia or assisted suicide were carried out without the explicit request of the persons involved.

3.6.2 Making end-of-life decisions

A number of factors have been identified as impacting the prevalence of end-of-life decisions in the ID population. According to Bekkema et al. (2014a), in at least 20% of cases relating to decisions to start or continue a treatment, factors such as quality of life and well-being (52.5%), the wishes and preferences of the families (23%) and wishes of the individuals (21.3%) were considered to be important. In at least 20% of decisions to forgo treatment, factors such as futility of treatment (38%), quality of life and well-being (36.7%), the physical strain of the intervention (27.9%), wishes and preferences of family members (27.8%) and emotional strain on the person (25.3%) were important. These findings were also reflected in the findings of studies undertaken by Wagemans et al. (2010, 2013, 2013a). The motivation to make a specific decision varied as indicated in the preceding section. However, the fact that a person had an ID, issues in relation to quality of life and the timing of conversations were seen to influence the end-of-life decisions made.

Having an ID was seen to impact on end-of-life decision making. Wicki & Hättick (2017) found a decision to withhold treatment was made in 18.9% of all residents but occurred most often for those with an ID (21.2%) when compared to people with other forms of disabilities (14.3%). Decisions to withdraw artificial nutrition or respiration were made significantly more often for those with an ID (46%) when compared to those with other forms of disability (11.7%). The decision to withdraw treatment was made in 18% of all residents but occurred most often for those with an ID (21.2%) when compared to people with other forms of disabilities (14.3%). These authors condensed data relating to withdrawing artificial nutrition and respiration and abandoning treatment into a single category entitled *"withholding life prolonging treatment"*. Decisions were made to withhold life-prolonging treatment, in 46% of cases involving people with an ID, in comparison to 24.7% of cases relating to those with other forms of disabilities. Having analysed the data using binary logistic regression Wicki & Hättick (2017) found that end-of-life treatment/care decisions were made twice as often for people with an ID when compared to those without an ID. Decisions to withdraw life sustaining treatment was made more often, for those with greater degrees of disability.

When conversations about end-of-life care take place also influenced the end-of-life decisions made Both Wagemans et al. (2010) and Wicki & Hättick (2017) identified a higher prevalence rate of end-of-life decisions in their studies when compared to other studies. Wagemans et al. (2010), concluded that 60% of the residents in their study had an end-of-life decision recorded, and Wicki & Hättick (2017) identified such decisions in 70% of cases. These results are higher when compared to the percentage recorded in other studies such as the 44% reported by van der Heide et al. (2003).

Wagemans et al. (2010), suggest that this higher percentage rate could be accounted for by the fact that discussions with patient representatives occur at a much earlier stage in the trajectory of a disease in the service they researched, in comparison to other services. Wicki & Hättick (2017) suggest that the higher rate found in their study, could be accounted for by their interpretation of *"pain relief or symptom control"* as a possible end-of-life decision. In addition, the chance of a decision to withdraw life sustaining treatment being made was found to be three times higher where an advance care directive was in place

The issue of quality of life featured strongly in a number of studies. Bekkema et al. (2014 a) identified that over 92.6% of professionals believed that considerations regarding quality of life are most important when considering burdensome medical interventions. In contrast to this, according to Wagemans et al. (2013a), none of the physicians interviewed in their study, stated directly that quality of life was a factor in their decision making process. However, based on statements made by physicians it did appear, according to Wagemans et al. (2013a), that a decline in the quality of life an individual did influence the decisions made by doctors, in conjunction with the medical condition of the individual.

Physicians indicated that they delegated assessment of quality of life, in the main, to family members. In a further study undertaken by Wagemans et al. (2013, p.768), quality of life was a significant concern of family members who said they could not let the individual involved "*go on like that"*. Their decision making was motivated by issues relating to the quality of life of the individual, especially if the quality of life of the person was perceived to be declining. Wagemans et al. (2013) suggested that factors such as quality of life and well-being should only be determined by the individual with ID themselves. Therefore, they concluded that where quality of life influences the decisions being made, more needs to be done to include people with ID in the decision making process.

3.6.3 Inclusion in the decision making process

The empirical literature indicates that a wide variety of individuals are included in decisions relating to end-of-life care. These include family members and health professionals including doctors, nurses, care staff and legal professionals. As indicated in section 3.2.1 there is limited evidence that people with an ID are included in end-of-life decisions or advanced care planning.

In fact, not everyone believed that people with an ID should be involved in making these decisions. This was identified by Bekkema et al. (2014) who found that only 43.6% of professionals felt that the wishes of the person with ID should lead the decisions making process and only 2.9% in the case of those with a severe to profound level of ID had their wishes considered. In the main, these decisions were taken by family members and health professionals.

Wagemans et al. (2010) identified that all end-of-life decisions were made by doctors and in 22 of the 27 cases identified in their study, a second opinion was sought. Families were involved in these decisions in almost half of cases. Wicki & Hättick (2017) identified a higher level of participation by family members in comparison to Wagemans et al. (2010). Family members were involved in decision making in 120 of 164 cases (73.2%). Legal representatives participated in 142 of 164 (86.6%) according to Wicki & Hättick (2017), whereas Wagemans et al. (2010) did not report any evidence of legal representatives being involved. Nurses were heavily involved in making decisions in 136 cases (82.9%) (Wicki & Hättick, 2017) and Wagemans et al. (2010) identified that nurses were involved in decision making in all cases in their study.

These findings contrast with a further study by Wagemans et al. (2013 a), which indicated that apart, from doctors, no other health professionals were consulted when end-of-life decisions are made in conjunction with family representatives. While the authors did not proffer a rationale for this, the facts that the Netherlands is unique in having specially trained ID physicians may somewhat account for the lack of consultation with other professionals.

Not only were a wide variety of individuals involved in decision making at end of life, the weight of influence of these individuals also varied. According to Wagemans et al. (2013 a) physicians always consulted with family members when making end-of-life decisions and gave great weight to the opinions of family members. While physicians consulted with care staff with respect to test results and changes in the individual, they did not appear to give much weight to the contribution of care staff. This finding was also reflected in the findings of Bekkema et al. (2014) who identified that the wishes of family members (25.7%) were given greater consideration than the wishes of the person with ID (15.7%) or professional perspectives (12.1 %) when making decisions. Professionals and, in particular, care staff felt that the wishes of families should be the decisive factors in decisions where the person lacked the capacity to decide. In contrast to these findings, Tuffrey-Wijne et al. (2013), found that while staff in ID services found it almost impossible to go against the wishes of family members, this was not the case for medical professionals. In this instance, doctors were quite clear that their responsibility was to the patient first, not the family.

Family members experienced considerable burden, when making decisions with and for their loved ones. McKenzie et al. (2017) found that families expressed divergent views on when to commence advance care planning. Some families wished to initiate these discussions at the point of diagnosis of a terminal illness. Other families believed that the process should begin when those involved were *"ready"* to start. In one instance, it took three years before a family was ready to start the process.

The authors indicated that, in this instance, those involved questioned their decision to wait so long, when the process commenced. Families who started the process early were happy with the decision. As one family stated:

> *As hard as it might be, get the discussion going, get something put in place* (McKenzie et al., 2017, p.1092).

Emotions can run high when families are making decisions for their loved one (Bekkema et al. 2014). In some instances, families questioned the decisions they had previously made for their loved one. This was particularly true for those who had to make decisions for people with a severe level of ID, as they were least able to consult with their loved one (Bekkema et al. 2014). Families were overwhelmed due to the dependency of the person and this was particularly true in relation to medical decisions such as nasogastric (NG) or percutaneous endoscopic gastrostomy (PEG) feeding. Families were particularly insecure, as found by Bekkema et al. (2015), where they felt they were deciding about the person's life or death. In these instances, families required the support of others.

Many families were unsure of the boundaries associated with making decisions for others; many of them were unsure of the legal parameters and felt a strong moral responsibility to make decisions. Some participants had been unaware that the doctor involved was legally responsible and had the final decision in terms of treatment and felt a considerable burden when making a decision they believed they were solely responsible for (Wagemans et al. 2013). In an effort to provide a more structured and less stressful approach to advance care planning, and to ensure it happens in a timely manner, McKenzie et al. (2017) suggest that the advance care planning process could be linked to person centred planning processes routinely used in ID settings to support people with an ID to make decisions about their lives.

To conclude this section, the majority of studies relating to end-of-life decision making are small scale qualitative studies, which explored the perspectives of families, staff and people with ID. The majority of studies were undertaken in the Netherlands. These factors limit the generalisability of these findings. However, a number of factors relating to end-of-life decisions were identified across studies. Firstly, people with an ID are rarely involved in decision making at end of life, and in some instances, professionals did not feel they should be involved in decision making. It is evident that a wide variety of family members and professionals are involved in end-of-life decision making.

Examples of end-of-life decisions include withholding NG feeding or other therapeutic interventions, DNRs and use of palliative sedation. While happy to be involved in decision making, families felt the burden of this, especially where there were difficulties consulting with the person involved.

In some instances, families were unsure of the legal parameters around making end-of-life decisions. A number of factors, such as the fact that the person had an ID, and when conversations about death and dying occurred, impacted on end-of life decision making. Other factors, such as quality of life and family wishes also impacted decision making. In the majority of cases, the wishes of family members had a significant impact on decisions made at end of life.

3.7 Discussion

The purpose of this scoping review was to establish what is known about end-of-life care and decision making practices in the ID population. The review also sought to identify the methodological approaches used in these studies. A total of 25 studies, which satisfied the inclusion and exclusion criteria were identified between the years from 2003 to 2018. A variety of research methodologies were identified. The majority of studies (68%; n=17) used qualitative approaches and the remainder used quantitative approaches (24%; n=6) or mixed methods (8%; n=2). The sample populations of these studies varied, ranging from six (Morton- Stance & Schafer,2012) to 109 (Tuffrey-Wijne, 2013). For quantitative studies, sample populations ranged from 248 staff (Bekkema et al. 2014) to 543 (Tuffrey-Wijne et al. 2008).

Common methods of data collection included interviews or focus groups predominately. Questionnaires and surveys and in one case a check list was developed by the authors to review decedents medical files (Wagemans et al. 2010). As previously stated, two studies (McCarron et al. 2018; Ryan et al. 2010) used mixed methods. However, in the case of McCarron et al. (2018) qualitative approaches predominated. The authors originally proposed to administer the Voices questionnaire as a paper-based questionnaire, completed with the assistance of a researcher. However, during the piloting phase, it was recognised that large volumes of rich narrative was not being recorded and the questionnaire was then administered in the form of a semi-structured interview.

Studies in the field of end-of-life care in the ID population have been undertaken across a number of jurisdictions, raising an issue in relation to the comparison of research findings. Firstly, the majority of studies are undertaken in western countries mainly in the Netherlands, UK and Ireland. This makes comparison of findings difficult given differences in how ID is defined and how services are provided across jurisdictions. For example, the process of deinstitutionalisation is at a more advanced stage in Nordic countries, when compared to the progress made in closing congregated settings in Ireland. Differing national polices and legislation also makes cross comparison of studies difficult.

Another factor, specific to the Netherlands, where the majority of studies were undertaken, is the fact that this country has trained specialised ID physicians, some of whom have accessed palliative care education.

Therefore, unique to this jurisdiction, people with an ID and their families have access to ID physicians, specialised in palliative care. Thus, the level of specialist support available in the Netherlands differs from that available in many other European counties. Ireland and the UK are unique in having nurses specially trained in ID, again impacting on the generalisability of findings from these countries.

A number of different sample populations were recruited to these 25 studies. A minority of studies focused on people with an ID. Four of these studies included people with a mild to moderate level of ID, and one focused on individuals across the ID spectrum. The limited amount of research undertaken with people with ID may be reflective of the fact that research undertaken with families and staff indicates that people with an ID are not informed of their diagnosis (Tuffrey-Wijne et al. 2010). Therefore, these individuals cannot be easily recruited to studies seeking to ascertain their perspectives on end of life issues. Two of these studies included people who did not have a terminal diagnosis, again alluding to the difficulties in identifying people with an ID and a terminal diagnosis to include in research studies at end of life. In addition, issues arise in identifying appropriate methodologies for the inclusion of people with a severe to profound level of ID. Many of those with a severe to profound level of ID, may use augmentative forms of communication and, as previously mentioned will require support from those who know them well to express their will and preferences (Tuffrey-Wijne et al. 2007).

Seven of these studies interviewed staff only (McCarron et al. 2018; Bekkema et al. 2015; Todd et al. 2013; Wiese et al. 2012; Ryan et al. 2011; McCarron et al. 2010; Li & NJ, 2008) and one study interviewed family only (Marlow & Martin, 2008). One study reviewed the case files of decedents (Wagemans et al. 2018). One study interviewed families and staff (Bekkema et al. 2014) and two studies involved people with an ID, families and staff (McKenzie et al. 2017; Tuffrey-Wijne et al. 2010). Bekkema et al (2014) used a case study approach to identify staff and families' perspectives of providing end of life care to a specific individual with an ID. Tuffrey-Wijne et al. (2010) used an ethnographic approach to explore the experiences of people with an ID who were dying from cancer, and those of their families and staff. McKenzie et al. (2017) interviewed people with an ID, families and staff involved in advance care planning.

The research undertaken in this area, is diverse. It focuses on people with an ID, family members and health professionals from numerous backgrounds including, doctors, nurses, and social care workers. Studies have been undertaken with professionals working in a variety of services including specialist community and residential ID services, hospital and hospices.

These studies have been completed across multiple jurisdictions, with differing forms of service provision. However, despite the issues identified above a number of themes emerged from the literature encompassing the inclusion of people with an ID in their end-of-life care, families and staff perspectives on providing end of life care, conversing about death, dying and end of life, service issues in providing end of life care, and end-of life decision making in the ID population.

The majority of research undertaken with people with an ID, has been undertaken with those with a mild to moderate level of ID. This research suggests that these individuals have differing perspectives on being informed of their diagnosis and careful attention has to be paid to the decision to disclose or not. Where people were happy to discuss issues relating to death and dying and their end-of-life care, the literature would suggest that being in control and aware of one's diagnosis was important to them (Bekkema et al. 2016). In addition, people with an ID expressed opinion relating to practical issues such a pain management and having their preferences met. They also emphasised the importance of continuing to engage in activities and living their lives while at end of life. They also identified the importance of their support network and having people to make decisions for and with them (Tuffrey-Wijne et al. 2013). This finding alludes to the importance of relational autonomy when providing end-of-life care for people with an ID.

With respect to the views of family members and staff, it was evident that both parties are committed to being involved in supporting the person at end of life. Despite this commitment, it is also evident that providing this form of care is complex and all stakeholders need support. The literature would suggest that families struggled to identify the care needs of their loved ones as they transitioned to end of life and tried to achieve a balance between ensuring their end-of-life needs were met while supporting them to continue living as full a life as possible (Todd et al. 2013). Families felt it was very important that staff and families cooperated together. Where cooperative relationships developed these were valued and were of great support to family members. Where these relationships broke down, it caused distress to family members and staff. Families recognised in some instances that staff within ID services had formed strong bonds with the person at end of life and that these staff had become a second family to those involved (Bekkema et al. 2015).

In many cases staff had developed a strong bond with the person at end of life which meant they knew the person well and could support and advocate for and with the individual involved. However, this emotional attachment could also be a burden as staff struggled to provide professional care while maintaining their composure at end of life. Staff in specialist ID services, in particular were committed to supporting people at end of life in familiar environments. However, in some instances, due to a lack of resources or experience, this could not always be facilitated, and people had to be transferred to hospitals, leaving these staff feeling they had failed the individuals involved (Todd et al. 2013).

However, staff prioritised providing appropriate end-of-life care and continued to support individuals when they were transferred to hospital in many cases (Wiese et al. 2013).

In many ways the research suggest that issues faced by families and staff, have a greater impact on breaking bad news, than issues faced by the person with an ID themselves (Todd et al.2013). Both families and staff struggled to engage in conversations about death and dying and end-of-life with people with an ID. While these parties frequently referred to issues relating to capacity and consent, as reasons for not engaging in these conversations with people with an ID, other issues were also found to be significant. These included organisational culture, lack of skills and knowledge on breaking bad news, avoiding emotional distress both for the person giving and receiving bad news and respecting the wishes of family members.

Issues arose within services with respect to providing end-of-life care to people with an ID. A lack of experience and competence in providing end-of-life care was compounded by the fact that people with an ID were not routinely referred to specialist palliative care services. In some instances, staff in ID services did not know which palliative care services were available to them (Ryan et al. 2011). Conversely, specialist palliative care staff lacked experience in supporting people with ID at end of life and struggled to communicate with and assess pain and other symptoms experienced by people with ID and found it difficult to communicate with them and gain their trust (Tuffrey-Wijne et al. 2013). ID staff also experienced a decrease in confidence when communicating with people with an ID at end of life. The importance of professional relationships and open communication was also emphasised by staff when providing end-of-life care (Bailey et al. 2016; McCarron et al. 2018) While the need to coordinate care and communicate effectively within and between services was emphasised, there was little evidence that this occurred.

With respect to end-of-life decision making, the research literature indicates there is little evidence of how end-of life care decisions are made with and for people with an ID. Evidence of decisions made mainly related to specific medical decisions such as the commencement or withdrawal of life saving/sustaining treatment. In the majority of cases, these decisions were made without the inclusion of people with ID (Witchki & Hallich 2017). Lack of capacity was the issue cited most often, but there was little evidence of capacity assessments being undertaken to objectively assess capacity.

Only one study identified people with an ID who were actively included in advance care planning in conjunction with their loved ones and support staff (McKenzie et al. 2017). People with an ID stated that issues in relation to effective communication and having their autonomous decisions respected were of most importance to them However, the research suggests that families and medical staff have a greater influence in the decision making process.

Despite this, both families and staff felt burdened when making decisions on behalf of another, specifically those with a severe and profound level of ID. Families in particular, experienced considerable burden when making decisions for their loved ones and were often times unaware of the legal parameters surrounding decision making (McKenzie et al. 2017).

To conclude, this review has identified that people with an ID are rarely informed of their diagnosis or involved in decision making regarding their end -of-life care. Where people with an ID have been consulted, in the main, they have been individuals with a mild to moderate level of ID, with little focus on those with severe to profound level of ID, who will need additional supports in order to participate. The studies in this literature review mainly captured either staff or family's perspectives in relation to their experiences of end -of -life care from a general perspective, with little information provided about the people who had died or were dying. The majority of these studies did not present in any great detail, information about the decedents involved, the context in which care was provided, or specific information about how end-of-life care was provided, and how decisions were made. In many ways, the decedents to whom the respondents referred, remained largely invisible and silent, and the perspectives of families and staff were presented in a distanciated manner which failed to reveal what happens to people with an ID on their end-of-life journey.

There were exceptions to this; Wagemans et al. (2010) captured specific information about aspects of end-of-life care and decisions made for specific individuals with an ID, who were supported in specialist services. However, only their medical notes were reviewed, not their entire case files, which documented all aspects of their lives, including their overall history within services, and supports and services they accessed outside of their medical needs. Therefore, only medical decisions were discussed in this study. In addition, the perspectives of those involved in making these decisions or their motivation for making these decisions was not captured in this study. As previously stated, one study interviewed families and staff (Bekkema et al. 2014) and two studies interviewed people with an ID, families and staff concurrently (McKenzie et al. 2017; Tuffrey-Wijne et al. 2010). These three studies are unique in that they captured the characteristics of the decedents involved and how and where end-of-life care was provided to them. They further captured the perspectives of families and staff, within the context in which care was provided and decisions were made.

The detailed narratives in these studies, shed some light on how and where end-of-care is provided to people with an ID. However, despite the input of these studies, as stated by the European Association for Palliative Care (2015) people with an ID largely remain an *"invisible population"* and further research needs to be undertaken to establish what happens to this population at end of life. This is particularly true for those with complex support needs such as those with moderate to profound levels of ID.

As previously mentioned, people with an ID present with varying levels of capacity and communicative ability. Therefore, a variety of research approaches will be required to identify what happens to people with an ID at end of life, how they are supported and how decisions are made in relation to their end-of-life care. Given the importance of the supports provided by both families and health professionals, the perspectives of these groups, also need further exploration.

Focusing on those who are already deceased, from a research perspective would allow approaches such as the medical reviews undertaken by Wagemans et al. (2010) to be broadened to include full case reviews, providing detailed information about the individuals themselves who had died, and their end-of-life journey. The perspectives of the families and staff working in specialist ID residential services could also be sought to add context to how the end-of-life care of these individuals was provided, and how end-of-life decisions were made with and for these individuals. The perspectives of service managers could also be sought to identify organisational issues impacting on the end-of-life care of these specific decedents.

The use of multiple sources of information, from documents and case files, and the inclusion of staff's and families' perspectives, in conjunction with service managers, will provide a more robust and comprehensive picture of what happens to people with an ID at end-of-life, how they are supported and by whom. It will also probe the context in which end-of-life decisions are made, the form these decisions took, when and why these decisions are made and who makes them. This study seeks to provide this comprehensive picture of how end-of-life care is provided to people with an ID and how end-of-life decisions are made. The methodology for this study will now be outlined in Chapter 4.

Chapter 4: Research Design and Methods

Introduction

This thesis seeks to describe and analyse end-of-life care supports and decision making practices in specialist ID residential services. This chapter first presents the aims and objectives of the study, followed by an overview of the epistemological stance underpinning the research and the case study methodology identified as best suited to inform the development of this study. Secondly, I describe and explain how a multiple embedded case study methodology was developed. The methodology, research population and sampling strategy are described. Finally, approaches to data collection and analysis are delineated and ethical considerations are addressed.

4.1 Research Aims and Objectives

The overarching aim of this study is to describe and analyse end-of-life supports and decision making practices in specialist ID residential services.

4.1.1 Research objectives

1. To identify, describe and analyse end-of-life care supports provided to people with an ID in specialist ID residential services.
2. To describe and analyse family members' and staff's experiences and perspectives of the end-of-life care of people with an ID in specialist ID residential services.
3. To determine the involvement of people with an ID in end-of-life decision making.
4. To describe and analyse the end of life decision making practices of family members and front-line staff in specialist ID residential services.
5. To identify organizational polices and perspectives specific to end-of-life care and decision making practices within specialist ID residential services.
6. To explore the use of advance healthcare planning in specialist ID residential services

4.2 Epistemological Stance

In undertaking this study, I required a clear and structured approach that would facilitate me to describe a complex problem, using a range of documentation and sources of information and thus began to explore a range of methodologies which would facilitate this. This exploration of a range of methodologies lead me to case study research and the work of other eminent researchers in this field including Stake (1995), Merriam (2009), and Yin (2003).

The epistemological perspectives of researchers underpin how they conceptualise and undertake research. The work of both Merriam (2009) and Stake (1995) has been situated within a social constructivist paradigm (Hyett, 2014) whereas Yin (2004) has drawn from a positivist perspective.

Both Stake (1995) and Merriam (2009) favoured an interpretive or social constructivist approach to case study research and focused on how qualitative researchers construct knowledge by exploring how people made sense of their worlds and their experiences. In a social constructivist approach to case study research, the case study develops through the relationship between the researcher and research participants. The case study is then presented in such a way as to engage the reader and involve them in the exploration of the case.

Yins' perspective of case study research is underpinned by a realist ontological perspective which is positivist. Exponents of a positivist approach, such as Yin (2004), hold the view that an objective, mind-independent reality can be accessed and tested using a variety of research tools in a value free environment. Positivists believe in *'cause and effect'* relationships which can be tested by isolating specific variables and using both inductive and deductive reasoning to test theory and make findings.

A positivist stance as advocated by Yin (2003) was considered the best "fit" for this study for several reasons. Firstly, positivists believe that reality is stable and can be observed and described from an objective viewpoint (Levin, 1988) without interfering with the phenomenon being studied. Thus, genuine, real and factual happenings, such as the end-of-life care of an individual, could be studied and observed scientifically and empirically and elucidated by the way of lucid and rational investigation and analysis.

Secondly, positivists believe in *"cause and effect"* relationships, where one event (the cause) causes another event to happen (the effect). These relationships can be tested by isolating specific variables and using both inductive and deductive reasoning to test theory and make findings. This positivist perspective is reflected in the way the methodological approach for this study was developed. In this study the relationships to be explored, i.e. the relationship between an individual with an ID, at end of life and the family members and frontline staff supporting them were identified prior to beginning data collection, specific research tools were used for data collection and both inductive and deductive reasoning was used to generate results.

Thirdly, as previously stated, this study drew on data from a wide range of data sources, which can be difficult to manage and analyse for a novice researcher. Yin (2004), advocates a structured approach which provided this researcher with a clear process for undertaking this study. In his approach to case study methodology Yin (2004) identifies the need for a clear study protocol where all aspects of the case are measured and appropriately described.

Yin (2003) suggests that researchers should be pragmatic about the commonalities shared by quantitative and qualitative research approaches and avail of both in the development of appropriate research proposals and protocols stating that

> *"Regardless of whether one favors qualitative or quantitative research, there is a strong and essential common ground between the two"* (Yin, 2003, p.15)

Yin (2009) advocates a rigorous process for data collection, focusing on capitalizing on the described skills of a case study investigator, undergoing training for a specific case study approach, the development of a protocol for the investigation, the screening of the case study nominations (making the final decision regarding the selection of case) and conducting a pilot study. According to Kim (2014, p.15) the *"structured approach to data collection"* central to a positivist approach to research might be the only way of ensuring consistency where multiple case studies are being undertaken across several research sites, as is the case with this study.

The research design of this study will now be presented.

4.3 Research Design

When identifying a research methodology, it is important to be mindful of the focus of the research topic. Addington-Hall (2009), has suggested that undertaking research in end-of-life care is challenging due to the ethical and practical issues that arise because of the vulnerability of each individual at end of life. This is even more relevant, in the context of this study, when exploring the end-of-life care of people with an ID who could be viewed as vulnerable across their life trajectory. In addition, end-of-life care does not focus solely on the individual involved, but also on their families, before and after death (WHO, 2015). Given the challenges encountered in researching end-of-life care, a rationale, as to why case study research was considered appropriate for this study will be presented in the next section.

4.3.1 Rationale for case study methodology

There are several key characteristics of case study research methodology which can facilitate in-depth insights into end-of-life care. Firstly, case study research methodology affords researchers a greater level of flexibility than other research approaches (Hyett et al, 2014) and is a suitable approach to answer many research questions posited by nurses, given its adaptability to real world contexts (Luck et al 2006; Payne et al, 2007; Donnelly & Wiechula 2012; Taylor & Thomas-Gregory, 2015; Harrison & Mills, 2016).

Secondly, case study research enables researchers to explore complex situations, to gain a deep insight into phenomena, critical events, policy-based initiatives or service-based reforms which require analysis in a real-world context (Crowe et al 2011; Casey & Houghton, 2010).

This is because case study research methodology allows researchers to avail of a broad range of research methods, drawing from a variety of data sources and this can be of great value in addressing data collection issues as well as ethical issues encountered in researching end-of-life care (Payne 2007; Ingelnton & Davies, 2009) where;

> *"[S]ituations are complex; the real-world context of the service is central; multiple perspectives are required; flexibility is desirable; research needs to be congruent with clinical practice; there is no obvious suitable theory and other methods present practical difficulties".* (Walshe et al, 2004, p.681).

Third, within the context of this study, the use of case study methodologies was deemed appropriate as the characteristics of end-of-life care mirror the approaches used in case study research (Walshe et al, 2004; 2007; Walshe, 2011). Walshe et al, (2004, p. 678) classify end-of-life care as a "*complex, patient focused, context dependent"* practice and hypothesize that these characteristics are reflected in the case study research approach due to

> "*its breadth, its collaborative approach, its recognition of complex contexts and the use of multiple research methods*".

In sum, the flexibility, the broad range of research methods, and the appropriateness to the study of end-of-life care, of case study research methods, enabled me to explore the end-of-life care supports available to people living in specialist ID residential services. It enabled me to draw on a range of data sources, and multiple perspectives including those of family members and professionals. This allowed the identification and analysis of how of end-of -life care is provided, and end-of-life decisions are made across multiple specialist ID residential services.

4.3.2 Multiple case study design

A variety of different approaches can be used when designing a case study methodology with one of the main decisions centering on the use of single or multiple cases. In essence, single case study design focus on one specific case, usually a case that would be defined as unique whereas multiple case studies focus on more than one case. In single units of analysis, the case is examined from a broad holistic perspective whereas in embedded design, specific aspects of cases are the focus of enquiry (Yin, 2009; Casey& Houghton, 2010). The use of multiple case study design is a mechanism to generalise from case study research (Tight, 2017). In comparison to single case studies, multiple case studies allow for a more expansive examination of a research topic (Yin, 2003). Whilst single case studies provide us with a unique insight into the context of each specific case, multiple case studies allow for analysis of data from both within each individual case and across multiple cases (Baxter & Jack, 2008; Stake,1995).

This allows the researcher to identify similarities and differences between cases and produces more generalizable and comprehensive findings. Thus, I have chosen to use a multiple case study approach to produce a comprehensive understanding of how end-of-life care is provided to people with an ID in specialist ID residential services in Ireland and how end-of-life decisions are made.

Having established that a multiple case study approach was most appropriate for this study, a further challenge was to determine which research methods to deploy in order to gather and analyse data. Given the difficulties undertaking research in end-of-life care, researchers have been advised to draw on *'the full range of available research methods using the one that most appropriately answers the question in hand'* (Addington-Hall, 2009, p.4). A variety of approaches to research can be employed which, historically, have been divided between two specific methods i.e. qualitative and quantitative.

Whilst primarily associated with qualitative approaches to research, case study research methodology has expanded into the field of mixed methods where quantitative and qualitative methodologies entwine (Yin, 2003; Tight, 2017; Creamer, 2018) and multiple sources of date are used (Zhang, 2014). Specific to end-of-life care, both quantitative and qualitative approaches are increasingly used in case study research, providing researchers with a mechanism to bring together a wide variety of data sources to gather information and provide as complete a picture as possible of what is a complex subject (Addington-Hall, 2009; Ingelnton & Davies, 2009; Creamer, 2018). This is discussed in greater detail in sections 4.4. and 4.5. relating to data collection and analysis.

To conclude, given the aims and objectives of this study, and having reviewed a variety of approaches to case study design, it seemed logical that an exploratory, multiple-embedded case study methodology would enable me to capture the unique and highly individualised experience of family members and staff supporting people with an ID at end of life (Payne et al, 2007; Ingelnton & Davies, 2009; Walshe, 2011). This study sets out to document nine individual *"cases"* of people with an ID who have died while being supported by specialist ID services. Identifying the *"case"* as an individual with an ID, allows for the exploration of how each individual was supported at end of life from diverse perspectives, through accessing documentation and correspondence relating to the person such as their casefile and gaining the perspectives of those who supported them. The process for binding the case will be described and discussed in the next section.

4.3.3 Binding the case

It was Louis Smith (1979) who first defined a case as a *"bounded system".* Merriam (2009, p.27) defines the case "*as a thing, a single entity, a unit around which there are boundaries"* asserting that if a researcher can draw boundaries and present a case in a *"bounded"* context then they can identify it as a case study. Walshe, (2011), has identified bounded systems or *"cases"* as a person, programme, service, group, policy or instance of something which will be studied within a defined, time, place, event or activity. Selecting the case(s) is an important decision and much thought must be given initially to the type of case, which is to be chosen, i.e. the characteristics of each individual case. Gerring (2007, p.89) identified nine different characteristics of case studies, ranging from an example of an extreme case to a typical case. A typical case is a case which "*highlights what is normal or average"* according to Miles & Huberman, (1994, p.28).

Typical case sampling is a form of purposive sampling technique (Etikan et al. 2016). Specific inclusion and exclusion criteria developed to identify a typical case are presented in section 4.3. In case study research the process of establishing boundaries around the case or *"binding"* the case is similar to developing *"inclusion"* and *"exclusion"* criteria more commonly referred to in research methodology. Consideration was also given to binding the case within the context of time, place and an event/activity (Walshe, 2011).

In this study, each individual **case** is *"bounded"* within the context in which each case occurs, i.e. the provision of end-of-life care within specialist ID residential services, as the study was designed to explore the dynamic nature of end-of-life care **(event)** (see Figure 1). Each individual case study explored the end-of-life care of an adult with an ID, who had died within the previous two years **(time)**, who was supported by family and front-line staff, in specialist ID residential services **(place)**.

It was also imperative that cases were selected in such a manner as to allow access to what constitutes the **units of analysis** of the case, be that individuals, organizations etc. This required access to all documentation pertaining to the end-of-life care of the deceased individual, and access to family members and staff who had supported people with an ID, who had died within the past 24 months. The embedded units of analysis are family experiences and perspectives of end-of-life care and, staff experiences and perspectives of end-of-life care.

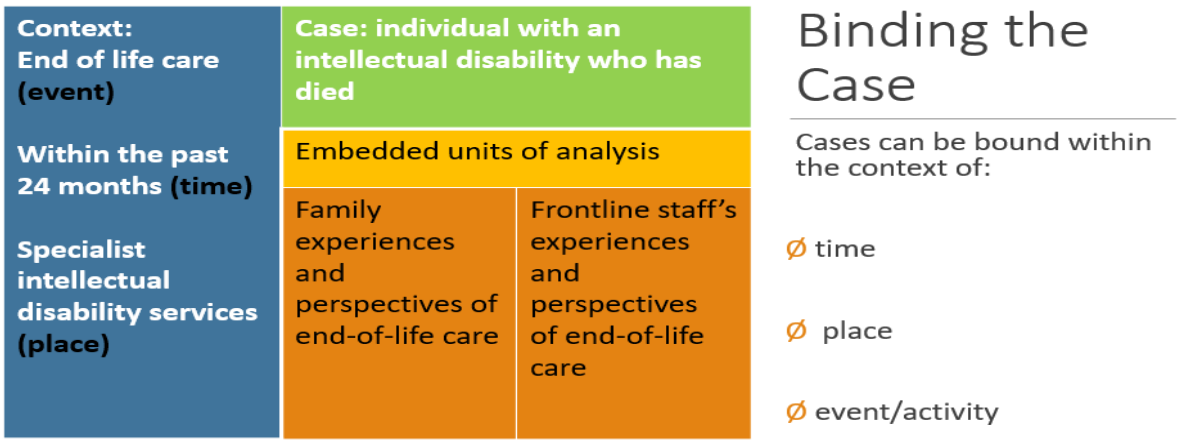


Figure 1: Description of the 'Bounded' Case Study

4.4 Research Sample and Accessing the Sample Population

The research sample for this population was identified across three separate organisations. A specific process for identifying and accessing the sample population was developed to ensure a consistent approach was used.

4.4.1 Accessing specialist ID services

A total of six organizations were initially approached and all responded positively, with requests for additional information. Two organizations indicated they did not provide end-of-life care and one did not respond to the additional information sent to them. Thus, the sample population was drawn from three organisations providing specialist services for people with ID in Southern Ireland, who met the inclusion/exclusion criteria for this study.

4.4.2 Inclusion/exclusion criteria

Having established the main constituents of the bounded case, a purposive sampling framework was employed to recruit participants, who met the inclusion and exclusion criteria for the study. This required the development of 3 specific sets of inclusion/exclusion criteria for:

- ID services
- the individual case i.e. the decedent with an ID
- study participants i.e. family members and staff

4.4.2.1 Inclusion /exclusion criteria for ID services

Inclusion Criteria

- Provide residential supports to people with an ID over the age of 18

Exclusion Criteria

- Do not provide end-of-life care support services.

4.4.2.2 Inclusion /exclusion criteria for individual case studies

Inclusion Criteria

- A person with an ID over the age of 18 who had died while availing of specialist ID services, within the previous 24 months.
- Where the deceased person was availing of services customarily provided within the specialist ID services, including access to primary and secondary services.

Exclusion criteria

- Where the family of the deceased person were not consistently involved in supporting the person (i.e. at least monthly contact).
- In the event of an unexpected or accidental death necessitating an autopsy.

4.4.2.3 Inclusion /exclusion criteria for study participants (family/ staff)

Inclusion Criteria

- Family members of adults with an ID who had died within the past 24 months.
- Staff who have supported adults with an ID who had died within the past 24 months.

Exclusion Criteria

- Family members who have not consistently supported people with an ID who have died over the past 24 months (i.e. at least monthly contact).
- Staff who have not consistently supported people with an ID who have died over the past 24 months (i.e. at least weekly contact).

4.4.3 Accessing the sample population or 'entering the field'

In case study research the process of accessing the sample population is often referred to as *"field work"*. Undertaking research in clinical sites, requires support from a wide variety of individuals and in a multi-site study, the researcher must navigate diverse communication systems and hierarchical structures, across different sites (Landers et al. 2012). Therefore, in this study, gaining access to these three sites and developing a good working relationship with the gate keeper or Principal Contact Person (PCP) within each organization was fundamental to the smooth execution of the data collection element of this study.

Figure 2 provides an overview of the process involved from the point of initial contact with the PCP to the identification of individual potential cases and accessing the sample population.

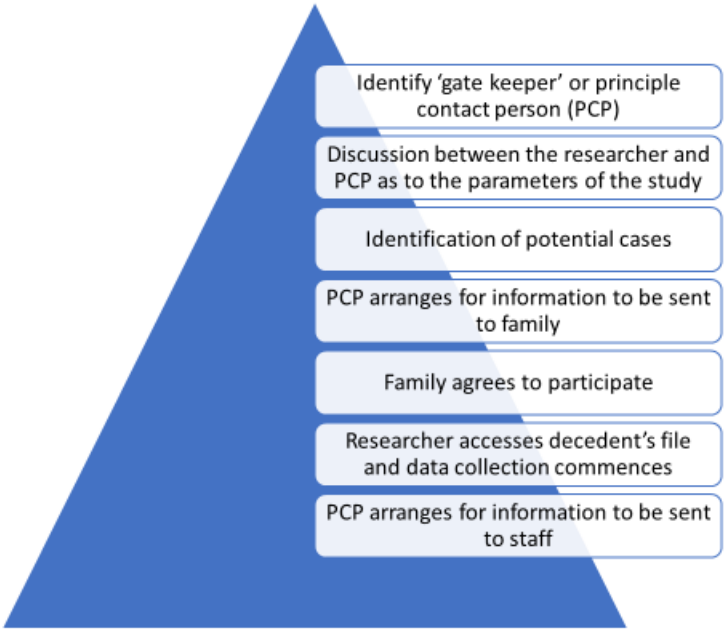


Figure 2: Overview of Process for Accessing Sample Population

Several meetings were scheduled to identify a PCP as an essential first step. While seeking permission to access the service was required from managers etc., the PCP needed to be sufficiently linked into front line services to be able to advise on how to best access family members and staff linked to each case. They also had to have enough knowledge to identify how and where to access all documentation relating to each case. During these discussions, the parameters of the study, specifically in relation to the inclusion and exclusion criteria were clarified. The PCP facilitated the identification of prospective cases and potential participants, i.e. family members and staff who cared for individuals with an ID who had died during the previous 24 months. The PCP within each organization were involved in the pre-selection of cases in conjunction with me, using the inclusion and exclusion criteria identified in section 4.3. The PCP was able to initially provide verbal information relating to each case, allowing me to adjudicate on typical cases without breaching client/family confidentiality.

Careful consideration was given to identifying or screening potential cases to identify cases which met the inclusion and exclusion criteria identified, i.e. a person with an ID who had died within the previous two years, while being supported by families and staff in ID services. Cases where an unexpected or accidental death which necessitated an autopsy were not included in the study sample.

This process required a significant investment of time on behalf of the PCP both during the initial discussions and in gaining access to the research population, case files and organizational documentation as the study progressed.

A total of 16 cases were initially identified that met the inclusion and exclusion criteria. On closer examination, these were reduced to 11. Three of the cases, were just outside the two-year timescale set, and thus were rejected. In the remaining two cases, the PCP was aware that, in one case the staff member who was most involved in supporting the person had gone to work outside of the jurisdiction and following enquiries, contact details for her could not be found. In another case, the PCP was aware that the family member who had the most contact with the service, had died. It was imperative to develop a good working relationship with the PCP within each organization to progress the study. The importance of access has been identified in other studies and is a central consideration in case study research (Stake, 1995; Landers et al. 2012). This aspect of the study took considerable time as, in some instances, documentation had been archived and needed to be retrieved.

As outlined in Figure 2, having identified potential case studies, initially family members were contacted by the PCP within each organization. A detailed protocol was established for contacting the family members and front-line staff (see Appendix 4), which specified that relatives of the deceased could only be approached once three months had elapsed since the death of their loved one to allow for a bereavement period. The PCP within each organization sent a letter of introduction (see Appendix 5), information leaflet (see Appendix 6), and a consent form (see Appendix 7), to each family member. Family members were also requested to consent to the researcher having access to the deceased person's file.

Throughout this process, no personal information relating to the decedents, family members, or staff, or access to personal files was provided until the parties involved had agreed to participate in the study. For some family members and staff, making the decision to participate in the study was a significant one and some potential participants spent a lot of time considering whether to participate or not. In one instance, a family member took the decision to participate over six months after receiving the documentation relating to the study and confided that the decision to participate arose from considerable reflection on her behalf and discussion with significant others. It was only when family members consented to participate in the study that the researcher was allowed access to all written documentation relating to the decedent and their family. The researcher then scheduled a time to interview the family member.

Concurrent with this, the same process as outlined in Figure 2 above was followed to identify staff involved in each case. The PCP within each organization was asked to identify staff members who supported the deceased person.

Staff members were then contacted as per the protocol and sent a letter of introduction (see Appendix 8), an information leaflet (see Appendix 9), and a consent form (see Appendix 10). Having established that the staff member was interested in participating in the study, the researcher then scheduled a time to interview the staff member.

A total of eleven families agreed to participate in the study initially. One family member withdrew due to health issues which presented after they had consented to participate, and one case could not be pursued as it was not possible to contact the staff member involved in the case as they had retired. Therefore, a total of nine individual cases were identified from across the three organizations. This sample size is within the parameters of the recommended samples sizes in case study research, which are reflective of a qualitative mind-set (Creamer, 2018). Authors such as Teddlie and Tashakkori (2009) and Creswell and Plano Clark (2011) recommend sample sizes ranging from 1- 15 cases. Creswell and Plano Clark (2011) recommended undertaking 4-10 cases with Teddlie and Tashakkori (2009) recommending an upper limit of 15 cases per study.

4.5 Data Collection

The data collection approach was influenced by the work of Yin (2003), who is considered to be an eminent researcher in the field of case study research. Yin identifies several prerequisites for the management of case studies, with a specific focus on approaches to data collection. These include identifying multiple sources of data, which will include archival data, documents, interviews and questionnaires, undertaking a pilot case study, creating a case study database and establishing a chain of evidence i.e. linking the data collected to the conclusions drawn in the case studies. These factors are discussed in greater detail in the remainder of this chapter.

4.5.1. Data sources

In undertaking this study, and in keeping with case study methodology, data was collected from a wide variety of sources including face-to-face interviews, questionnaires and a review of pertinent documentation (See Figure 3). A reflective diary and field notes (see Appendix 19) were also maintained over the course of the study.

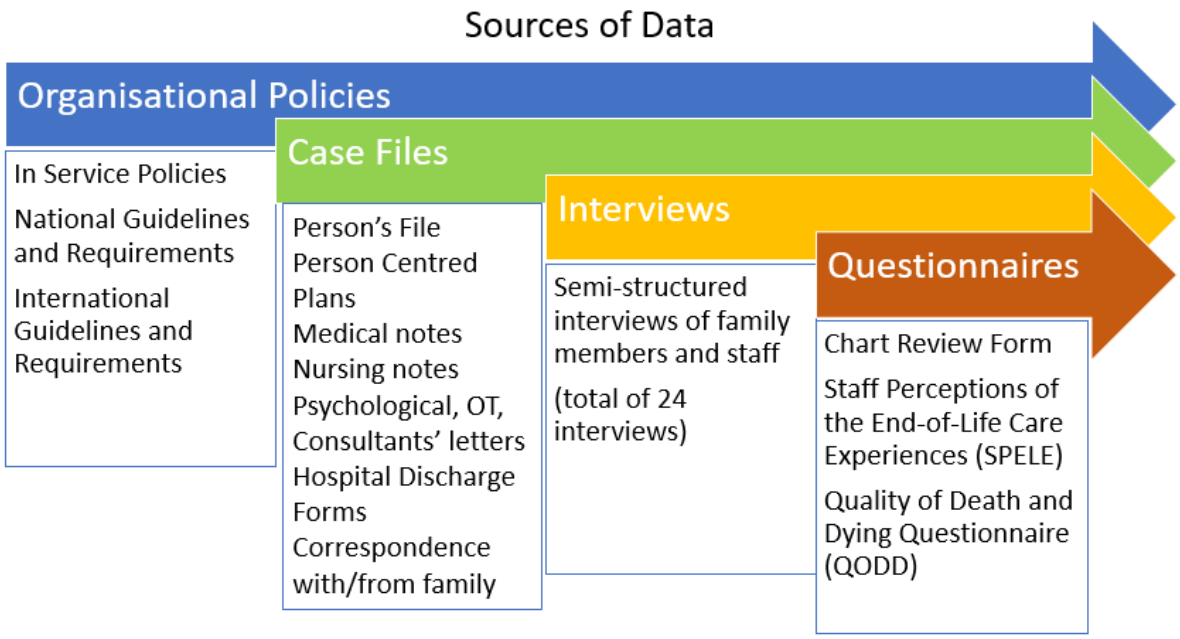


Figure 3: Data Sources

4.5.2 Data collection steps

Data was collected concurrently, using both quantitative and qualitative data collection methods, over a two-year period, from 2016 to 2018. The term *"inherently mixed'* identified by Teddlie and Tashakkori (2009) refers to the process of gleaning quantitative and qualitative data from the same sample source (family members and staff), as is the case in this study, during both data collection and analysis phase. The data collection process was undertaken in distinct steps and these steps and the research instruments used are identified in Table 1. While the data collections steps suggest a completely linear approach, these steps, in fact followed an iterative pattern. For example, the *"case file"* of some individuals was referred back to following the interviews, to clarify points made in the interviews or to add to the data relevant to each case, as were the transcripts from the interviews and the completed case studies.

Table 1: Data Collection Steps

Step 1	**The Profile of Home Questionnaire (see Appendix 11) was completed by the researcher and the gate keeper for each organization (Engelberg et al, 2006)**	
Step 2	Review of documentation such as organizational policies and decedents' files	
Step 3	The Chart Review Form was completed by the researcher having reviewed the decedent's file (Cornally et al. 2013) (see Appendix 12)	
Step 4	**(Part A)** Interview family members	**(Part B)** Quality of Death and Dying Questionnaire (QODD) (see Appendix 13) (Engelberg et al, 2006)
Step 5	**(Part A)** Interview staff	**(Part B)** Staff Perceptions of the End-of-Life Experience (SPELE) Questionnaire (Cornally et al, 2013) (see Appendix 14) QODD Questionnaire

Permission was granted by the developers of these questionnaires to use them in this study (see Appendix 15)

4.5.3.1Step 1: Profile of Home Questionnaire

The Profile of Home Questionnaire was completed for each individual organisation. The profile of home questionnaire comprises of 12 questions relating to the provision of GP services and the number of hospital/ accident and emergency referrals. The questionnaire also seeks to identify the number of deaths within each home and the availability of specialist palliative care services. This was completed in conjunction with the PCP for each organization.

4.5.3.2 Step 2: Documentation and policies

The use of documents as a form of data collection has been identified as an important aspect of case study research. Documents can serve several purposes including a role in substantiating, corroborating and enhancing data gleaned from other data sources and can add depth and context to each case study (Yin, 2009; Simons, 2009; Merriam, 2009; Stake, 1995). Documents come in a variety of guises including national polices, protocols, public records, personal papers, artefacts (Merriam, 2009), letters, email correspondence, minutes of meetings, administrative documents, newspapers, archival evidence (Yin, 2009), organizational and institutional reports including polices and individual medical and case files (Bowen, 2009). Documentation and policies relating to the organizations included in this study were reviewed and a review of the file of the decedent, who formed the basis of each individual case, was then undertaken.

Insights and information gleaned from documents added knowledge to the case study database and facilitated the detailed documentation of changes, relating to a decedent's case, over time.

Documents may not always be accurate and unbiased, and thus must be "*carefully used and should not be accepted as literal recording of events"* (Yin, 2009, p.103). The researcher must be a "*vicarious observer"* who is trying to identify the objective of those involved in the original development of the document as a record (Yin, 2009, p.105). The authenticity of documents must be assessed, and the researcher must be mindful of the reason why the documents were produced, or the information was recorded, as well as the accuracy of the record. An essential hallmark of these documents is that they are produced independently of the research study which distinguishes them from documents produced by the researcher. The latter might include documents such as research diaries or field notes or writing up a life history during a case study.

4.5.3.3 Step 3: Chart Review Form

The Chart Review Form (see Appendix 12) is the first aspect of the SPELE questionnaire developed by Cornally et al. (2013). The Chart Review Form was completed when each decedent's file was accessed and reviewed. The use of this form was of particular importance in this study as many of decedents had been supported in their respective organisations for decades and a large amount of documentation had amassed over this time. In the majority of cases, three full archive storage boxes of documentation were made available, per decedent by the PCPs within each organisation. The form provided a consistent, systematic process for the examination of decedents' files in order to identify contextual information relating to each individual's end-of-life care including cause of death, medications at end of life, pain and symptom management, advance care planning and patient/family distress.

4.5.3.4 Step 4: Family interviews and completion of questionnaires

Subsequent to the completion of the Chart Review Form family members were interviewed and the QODD was also completed by families at this point. Interviews are identified as an appropriate mechanism for data collection in end-of-life care as they build on the experience of the individuals involved. In addition, participants generally find sharing their stories with an attentive listener to be a positive one (Payne, 2009). In this study, face to face semi-structured interviews were undertaken. Individual interviews were considered more appropriate than focus groups given the sensitivity of the subject matter and the individuality of each person's experience and the individuality of each decedent's story. Semi-structured interviews were considered most appropriate for this study as interview questions are used to guide the interview without making the interview process so rigid as to prevent research participants from formulating or expressing their own viewpoints (Payne, 2009).

The use of semi-structured interviews also ensured consistency in the questions asked in each interview. The interview schedule (see appendix 16 & 17) was informed by a number of sources of information.

Initially, it was informed by the literature review undertaken as part of this study which informed my knowledge and understanding of end-of-life care specific to people with an ID. It was also informed by professionals in the field of gerontology, end-of-life care and ethics who reviewed the interview schedule. It was further informed by the aims and objectives of this study (see section 4.2) and was further refined following the completion of a pilot case study. While the interview schedule provided a useful *"guide"* to ensure all research questions were answered, in the main, interviews took a more conversational tone. In undertaking the interviews, the researcher first contacted potential participants by phone and informed potential participants about the study, as a follow up on the information provided on the information sheet that had been posted to them by the PCP.

The potential participants were then asked if they still wanted to be involved in the study. If they wished to continue, a time for the interview was identified. Each research participant was given the opportunity to identify where and when they wished to be interviewed. Two opted to attend the researcher's office and seven wished to be interviewed at home. Interviews were undertaken at times which were convenient to the research participants. At the end of each interview, the researcher requested permission to make a phone call either on the day, (if the interview was in the morning) or the day after the interview, to enquire if participants required any additional supports or to debrief.
Following the interview, respondents were asked to complete the QODD. Family members completed the QODD which comprises of conceptual domains including symptom and personal care, preparation for death, moment of death, family treatment preference, whole person concerns. This instrument contains 4 sections. Section A contains 4 questions on the relationship between the relative and the deceased. Section B has 8 items; C has 30 items with 1-7 scoring format. The final section allows for free text and comments. Validity and reliability of this instrument has been established, with good cross-sectional validity established (Engelberg et al, 2006).

As previously stated in section 4.5, data from multiple sources was triangulated to build each case story. The QODD was used in this study as it captured specific information in relation to the end-of-life care of each individual. Specifically, it provided an opportunity for participants to rate aspects of the quality of the death of the person ranging from poor to very good, providing detailed information for integration into each case study. In addition, the prescriptive nature of the QODD facilitated the free-flowing nature of the interviews with family members. Without its use, a more structured approach would have had to be taken to the interviews which, as previously stated by Payne (2009), might inhibit participants' ability to formulate and express their personal perspectives.

Research participants completed the questionnaires at the end of the interview. In some instances, research participants opted to complete the questionnaires there and then. Others wished to complete them later and were provided with a stamped, self-addressed envelope. In all but one case, families completed the questionnaires at home and posted them back.

4.5.3.5 Step 5: Staff interviews and completion of questionnaires

The process for conducting staff interviews was completed in the same manner as for families. Staff too were offered an opportunity to identify where and when they wished to be interviewed. The majority wished to be interviewed at work and this was facilitated by the PCP in each organisation. In two instances, staff wished to be interviewed outside of their work environment and this was facilitated by the researcher. In three instances, the interviews had to be rescheduled due to work pressures. These were undertaken at a later date. There were two distinct differences between the interview process of families and staff. Firstly, additional questions were added to the interview schedule for staff, (see Appendix 17) relating to organisational issues and policies. Secondly, as referred to in section 4.4.2 the staff completed both the QODD and the SPELE which will now be discussed.

The SPELE questionnaire, (see Appendix 14) developed by Cornally et al. (2013) was used for contextual data such as demographic data of staff and includes age, gender, current role, highest level of educational achievement, and education on advance directives/palliative care. It also measured staff perception of the end-of-life experience of decedents. The SPELE comprises of 8 sections. Section 1 relates to demographic detail and contains nine questions. Section 2 contains six questions on person and setting. Section 2 measures pain and symptom experience and contains two questions (1 scale identifying 13 symptoms and 1 global question). Section 4 has two questions (1 scale -11 items, 1 global rating scale) on personal acceptance, insight and control. Section 5 measures resident's preferences across three questions and includes two items measuring perceived level of control and desire for control. Section 6 relates to communication and contains three questions. Section 7 has three questions measuring distress and satisfaction. Finally, section 8 contains two questions on global ratings of care. The preliminary psychometrics have been tested (Cornally et al, 2013). The findings suggest that this is a promising questionnaire that can be used to explore end- of- life care.

Good content and inter-rater reliability were established by Cornally et al. (2016) except for pain and symptom experience, where slight–moderate agreement was identified between nurses and healthcare assistants. However, the questionnaire was designed for older adults in long term care, and this is the first time it has been used in an ID population.

The SPELE was used as it captured information relating to the end-of-life care of each decedent and afforded participants the opportunity to rate aspects of end-of-life care across a continuum. The integration of this data from the SPELE added to the richness of each individual case study. It also, as previously mentioned, facilitated more free flowing interviews than might have been the case, if this questionnaire had not been used.

4.5.3 Pilot case study

Yin (2009) advocates piloting a case after an initial draft of the case study protocol has been developed. From his perspective a pilot case is not considered to be a pre-test, rather it affords the researcher the opportunity to refine data collection procedures in terms of the content of the data and the processes to be followed while conducting the research.

With respect to the data collection process, following the pilot case, two modifications were made to the data collection process. Firstly, it was decided that staff should also complete the Quality of Death and Dying Questionnaire (QODD) (Engelberg et al, 2006) (see Appendix 13). The QODD is designed to capture data from the family perceptive, however it does allow for others who were directly involved with the individual at end of life to complete it. The decision to request staff to complete the questionnaire was taken following a conversation with a family member who had completed the form. This family member stated that her loved one was supported in residential services by staff members, who knew the person well, over a long number of years. She stated that these staff might be well placed to answer the questions asked in the QODD, as well as family members, given the staff's long-standing relationship with the individual involved. The pilot study was not included as one of the nine case studies in this thesis.

Secondly, it was evident that additional family members or staff might need to be interviewed to get a complete picture of the case, as different family/ staff were supporting the person at different times. In some instances, more than one member of staff might be interviewed in a case.
For example, a staff member mentioned a relevant incident they were made aware of but were not actually present for. Acting on this information, I then referred back to the decedent's file, identified the staff member who was present, who was subsequently invited to participate in the study and interviewed. This situation also arose with a family, where two family members were heavily involved in providing care for their family member and were present at different times whilst caring for the person involved.

4.6 Data Analysis

Owing to the multiple sources of data gathered over the course of this study, a variety of analytical approaches were used. Data analysis in case study research is heavily influenced by

> *"the investigator's own style of rigorous empirical thinking along with sufficient presentation of evidence"* (Yin, 2009, p. 127).

In each case study, the researcher is immersed in, and describes, the data. This process is repeated for each case, and cases may be reanalysed as part of a cross cases analysis in multiple case study research. Data collection, analysis and the writing up of the case occurs simultaneously.

In this study, descriptive interpretation of the data is undertaken. According to Sandelowski (2000, p335)

> *"although no description is free of interpretation, basic or fundamental qualitative description entails a kind of description that is low-inference"*.

These descriptions can be intense and revealing, providing highly detailed accounts which enable the reader to understand the people and events involved. This level of description

> *"moves the interpretation away from research-centric perspectives portraying instead the people, events and actions within their locally meaningful contexts"* (Yin, 2011, p.213).

These detailed descriptions allow for the exploration of complex situations, within their real world context, allowing researchers to gain a deep insight into phenomena, critical events, policy based initiatives or service based reform (Crowe et al, 2011., Casey &Houghton, 2010). According to Sandelowski (2000) qualitative content analysis is the approach of choice where the expected outcome of a study is a descriptive summation or interpretation of the data. In the case of this study, the data is summarised into individual case studies. The process for undertaking data analysis in this study is presented in the following section.

4.6.1 Data analysis process

The analysis of data from case studies is a complex procedure. Given the amount of data generated during the data collection process, a structured approach to data analysis is essential. Yin (2009) identified several data analysis strategies. In this study, the analytical process encompasses a framework to develop case descriptions/ build the case story, a strategy identified by Yin (2009, p.131) as being most appropriate "*where the original and explicit purpose of the study may have been a descriptive one"* as is the case in this study.

4.6.2 Building the case story

According to Yin (2009, p.130) all research studies have a story to tell. However, case study reporting is not simply storytelling although the inclusion of case story narratives or vignettes is useful in providing the reader with the essence of each individual case study. Case stories, like all stories, must have a beginning, middle and an end, and will typically be developed in one of three ways:

1. A chronological or biographical development of the case
2. A researcher's view of coming to know the case
3. Description one by one of several major components of the case

In this study, a chronological approach was taken to developing the case stories, based on the analysis of the documents, interviews, and questionnaires and cognisant of the research aim and objectives of this study. This approach included the development of a brief history of the person to identify their family circumstances, the number of years within the service and supports availed of. The person's general medical history was then compiled and specific information relating to their care prior to their death was identified. The perspectives of those supporting these individual, i.e. their family members and staff were also integrated into each case story (see Figure 4).

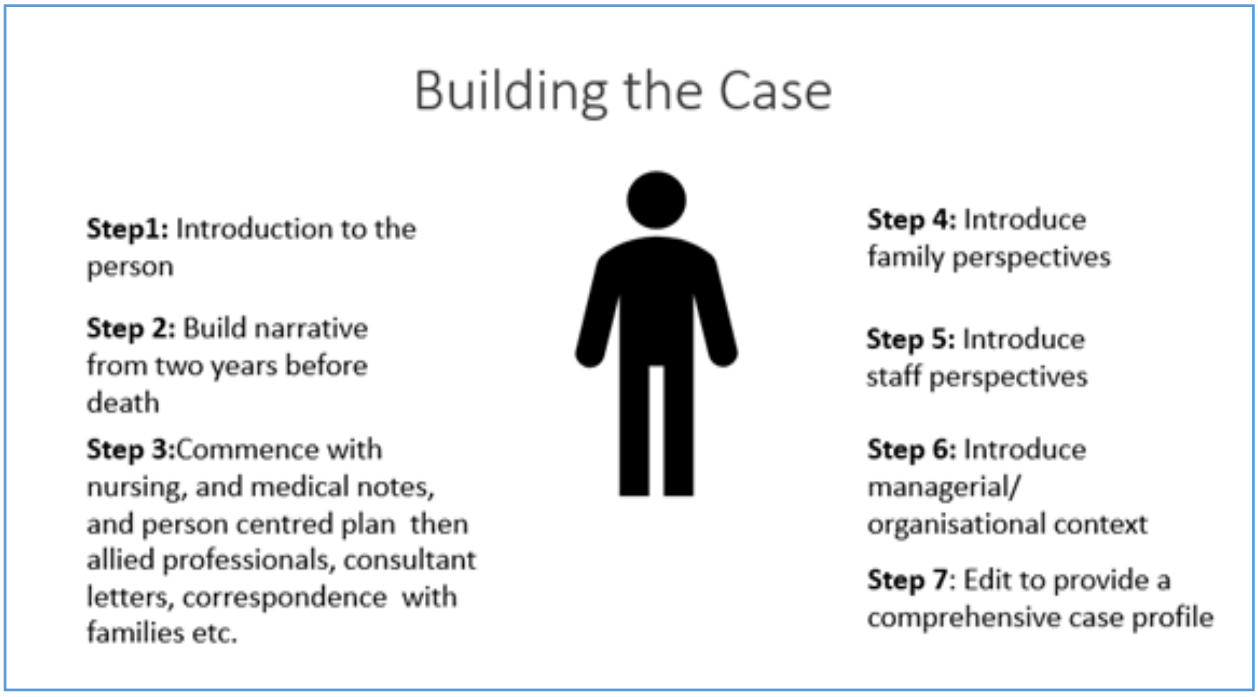


Figure 4: Building the Case story

This chronological approach is a "*special form of time-series analysis"* according to Yin (2009, p. 148). This form of analysis is of most relevance when a specific factor needs to be traced over time, and Yin (2009) asserts that chronology can give a richer and more insightful description of a case than other forms of time-series approaches as this approach can incorporate a wide variety of variables relevant to each case story.

This is of significance in this study, which has several embedded units of analysis, e.g. families and staffs' perspectives. The use of a chronological approach also ensured a clear picture of the individual involved is provided in conjunction with the perspectives of families and staff. The development of each case was an iterative and deductive process, with constant reading and rereading of the case file and interviews. The questionnaires were also continuously referred to. The cases themselves were constantly read and reread during their development. With respect to case 1, the first case developed, it originally contained 14, 562 words and was eventually distilled down to 2, 658. This process took much time, analysis and reflection, for each case study.

4.6.3 Developing a case study database

To manage the data collected and ensure an orderly approach to data analysis, a case study database was developed for each case. An efficient data management approach is considered essential and specialised software such as NVIVO can be very useful. However, irrespective of whether such software is used or not, the researcher must do "*the analytical thinking"* (Yin, 2011, p. 180). I considered the use of specialist software but chose to use a combination of pencil and paper along with word documents and a personal computer to engage with the data as this approach facilitated me in becoming immersed in the data.

A case study database is a repository of all data gathered in relation to a case. It includes, pertinent reports or records, the researcher's own notes, interview transcripts, interview recordings, and completed questionnaires relevant to the case. Patton (1990, p. 313) states that a case study database "*pulls together and organises the voluminous case data into a comprehensive primary resource package".* In this study, the database was comprised of a hard copy record of all documentation relating to each case which was maintained in a locked filing cabinet. This contained all the documentation relating to each case: the consent forms; the researcher's notes having reviewed the individual's file; the transcript of the interviews and the completed questionnaires. An example of the content of the case study database for Case 1, which will be presented in Chapter Five, includes:

- Researcher's own notes specific to the case including reflective notes
- Consent forms
- Chart Review Form
- Individual case notes (52 pages of A4 handwritten notes)
- Interview, (2 hours and thirty-two minutes for both family and staff; approx. 22 hours of recording in total, for all cases)
- Interview transcripts, (64 A4 typed pages)
- Questionnaires (4 per case; 36 questionnaires in total, for all cases)

While the amount of individual case notes varied, the majority amounted to between 50 and 60 pages of A4 handwritten notes. In one case, 90 pages of notes were compiled, as this individual had significant ongoing health issues and comprehensive nursing notes in particular, were maintained on this individual (Case 4). The majority of interviews for both staff and families, lasted for one hour each on average. In the main, staff interviews lasted an hour. For families, the shortest interview was 35 minutes and the longest was 75 minutes. A digital copy of the case file was also developed, all documentation was scanned and maintained on a password protected computer. Audio recordings of the interviews were also maintained along with a copy of each transcript. The data was thus organised in a manner which made sense to me, allowing for the data for each case to be easily retrieved over the lifetime of the study. The case study database also served as an audit trail to ensure a chain of evidence existed to enhance the rigour and trustworthiness of the study.

In case study research, data collection, analysis and the writing up of the case occurs simultaneously as this is an iterative process (Weber, 1990). Compiling all the data for each individual case afforded me the opportunity to familiarize myself with all the data I had collected, for each individual case and across cases. For each case, I began to read and reread my field notes and other documentation, listening to and reading the transcripts from interviews several times and reviewing the data from the questionnaires.

4.6.4 Document data analysis

Yin (2009) identifies the importance of the researcher identifying documentation relevant to the case and leaving other documentation, which is irrelevant to one side. This process was important in this study as, given that many of the decedents had been in residential care for most of their lives, the amount of documentation provided to the researcher was immense. As previously stated in section 4.4.in the majority of cases three full archive storage boxes of documentation had to be sifted through initially to identify data that was pertinent to their end-of-life care. It took between 12 and 24 hours to review documentation provided for each individual, with on average 18 hours being spent on reviewing, compiling, and transcribing the pertinent information for each individual.

Medical and nursing notes, medication charts and death certificates were carefully scrutinised, and the chart review form was used to collate much of this information. Social work and psychological reports along with other documentation deemed relevant to each case was also recorded in note form. This involved the direct transcription of the information from the individual file into an individual notebook, identified for each case. I also put comments in the margins, as to my observations relating to the information available within each file.

These field notes differed from the reflective diary used over the course of the study and contained only information and references to documents scrutinised in each case. Content analysis was then used to analyse the documents. This form of analysis was also undertaken to analyse the interview data and is discussed in detail in the following section. Additionally, quantitative data, was generated from the chart review form, documenting factors such as the number of hospitalizations the individuals underwent, GP and palliative care consultations visits, and number of family visits. This data was then integrated into each individual case study and further analysed during cross-case analysis.

4.6.5 Qualitative data analysis

Qualitative data analysis techniques were used to analyse the data from both the questionnaires and the interviews undertaken as part of this study. A total of three questionnaires were used in the study. Demographic information relating to the decedents, their loved ones and staff supporting them was derived from the questionnaires. The data from the following questionnaires was qualitized

- Chart Review Form
- Staff Perceptions of the End-of-Life Care Experience (SPELE)
- Quality of Death and Dying Questionnaire (QODD)

Qualitizing is an analytical strategy used to transform quantitative data from questionnaires into a narrative form which can then be analysed using qualitative approaches (Teddlie & Tasshakkori, 2009; Small 2011). This process involved using a qualitative content analysis approach to analyse the data generated from the questionnaires and this narrative is then integrated into each individual case study. For example, with respect to section 3 of the SPELE, which focuses on pain and symptoms experience at end of life, data relating to symptoms experienced and the level of distress caused by these symptoms was identified. This data was then compiled into a narrative which summarises the symptoms experienced by those individuals and the extent to which each symptom impacted on the individual.

A total of twenty-six interviews were undertaken and audio recorded during the course of this study. In keeping with Payne's (2009) perspectives on transcribing, I undertook the transcription of one third of the interviews in this study before employing the services of a professional transcription service. Payne (2009, p.149) cautions that transcribing is not something that is "*simply delegated to a secretary".* Careful attention must be given to the process of transcribing as this is the first step in the analytical process. The researcher must listen to all audio-recordings and check the transcripts for accuracy.

Transcripts should be read in conjunction with listening to the audio recordings as pauses, tone of voice etc may add context and additional understanding of the written word. O' Connell and Kowal (1995), cited by Payne (2007), emphasise the importance of prosodic and paralinguistic elements of transcription.

As previously stated, content analysis is the main approach used when analysing data in this study. As stated by Norwood (2009, p.347)

> *"The term content analysis refers to the process of analysing any type of narrative data for the purpose of identifying prominent themes, as well as the relationships or patterns among themes"*

Qualitative content analysis is a dynamic form of analysis which is both reflexive and iterative as the data is constantly modified to accommodate new data. As previously stated, while qualitative description is a form of low inference analysis, it does require some interpretation to understand the content of the data. In qualitative research, content analysis data is coded as part of the analytical process, but the codes are generated from the data itself and there is no requirement to re-present the data in any other form - people's descriptions of events remain as descriptions, their perceptions remain perceptions (Sandelowski,2000). In essence, qualitative content analysis, required the researcher to describe what the respondents in their study have said, either by reference to their spoken words when interviewed, or what has been written in documents. The researcher stays very close to these texts and, in the main, uses the words of the respondents involved.

Whilst Yin (2011) refers to the importance of coding, he does not provide detailed guidance as to how to undertake this process. Therefore, I also referred to the work of others such as Miles and Huberman (1994) for guidance. Descriptive coding was used as the function of descriptive codes is for the identification and labelling of what is in the data. In this study, these codes are generated from the data itself (see Appendix 18). I used a five step process to undertake the analysis of the qualitative date drawn from the approach of Yin (2009) and Miles and Huberman (1994), as identified in Figure 5.

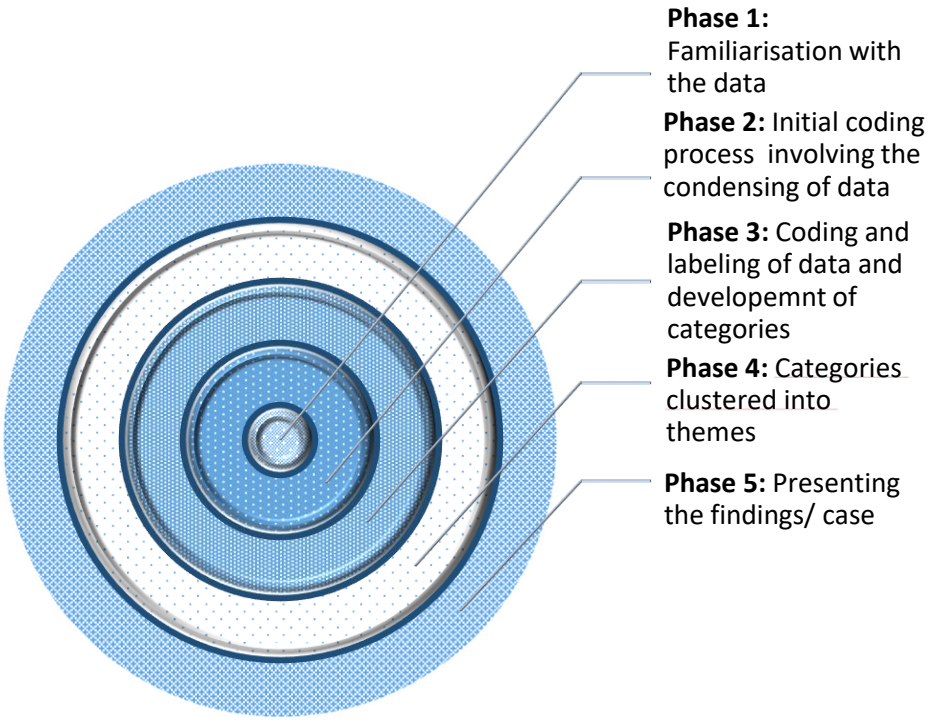


Figure 5: Five step Process for Data Analysis

4.6.5.1 Phase one:

As a first step in analysis, Yin (2011) emphasises rereading, relistening and getting to know one's field notes. This process is also an important part of developing a case study database, reflecting the iterative nature of qualitative analysis, as I became immersed in the data collected for individual cases and then across cases. The main object at this stage is become completely familiar with the data for each case.

4.6.5.2 Phase two:

At this point, I began to condense the data down into smaller statements, derived directly from the data itself. This allowed me to focus on content of importance, allowing me to get a *"feel"* for the data This was done by hand in the margin of the transcripts and in the documents available to me and by highlighting specific statements in the transcripts and documents itself.

4.6.5.3 Phase three

This phase saw the beginning of the initial coding process where I sought to sum up what is being said in the text and label the data in manner which accurately described its meaning. At this point, I began to attempt to interconnect the codes developed and categorised them on the basis of their relationship to each other and how they were linked together, using word documents. Throughout this time, transcripts were read and re-read, and recordings listened to again, notes and memos from my *"field notes"* and my reflective diary were also reviewed.

Miles et al. (2013) refer to the need for constant comparison of the emerging categories and the transcripts to ensure that the categories developed reflect the data collected from the interviews.

4.6.5.4 Phase four

In the fourth phase, the initial analysis and development of categories were again reviewed to identify similar or overlapping categories and these categories were then further reduced and refined and were then clustered together into the overarching themes identified in this study. Exemplars of the approach to the coding and development of these have been provided in the findings chapter and in Appendix 18.

4.6.5.5 Phase five

Phase Five involved a two-tier process, which involved the presentations of the findings of the study in two forms. Firstly, individual case stories were developed and outlined and then followed by the findings generated from the cross-case analysis of the nine cases.

4.6.6 Cross case analysis

In conjunction with the development of nine case stories, an additional analytical technique is applied in this study, namely cross case analysis. Cross case analysis is specifically used to analyse multiple case studies. This process involves the individual analysis of each case and aggregating the findings across cases. Cross case analysis has been identified as a form or integration or mixing of data (Creamer, 2018, Bazeley, 2009 2012). Data triangulation involves combining data from multiple sources of data, as is the case in this study across multiple sites.

> *'By comparing sites or cases, one can establish the range of generality of a finding or explanation, (*Miles and Huberman, 1994, p. 151).

In this study, data generated from individual case files, from the interviews from both staff and families, and from the questionnaires was integrated into each individual case study.

When completed, a cross case analysis of the individual cases is undertaken to identify commonalities and differences between the individual cases, using the same steps identified for undertaking an analysis of the individual cases. Each case was read and reread, to identify the commonalities and differences between cases. Emerging themes were initially categorised, and codes developed based on their relationship with each other. Broad themes were then developed to depict the commonalities identified between the cases. Where exceptions occurred between cases, these are also discussed in in the cross case analysis. The cross case analysis is presented in Chapter 6 of this thesis.

4.7 Rigour and Trustworthiness of the Research Process

Assuring the rigour and robustness of case study research is a challenge. Patton (1999, p. 1190) states the credibility issues associated with qualitative research are linked to

> "*rigorous techniques and methods for gathering high quality data that can be carefully analysed, the credibility of the researcher'* and a *philosophical belief in the values of qualitative inquiry"*.

There is no definitive mechanism for validating case study research (Tight, 2017). However, many explicit approaches which propose different mechanisms for addressing the issue of rigor in case study research have been identified. Internal and external validity is integral to the criteria for judging research quality along with trustworthiness, credibility, transferability, confirmability and authenticity (Denzin and Lincoln, 2011). Riege (2003) identifies credibility, trustworthiness, confirmability and dependability as concepts fundamental to addressing the issue of quality in case study research. Peshkin (1988) also emphasises the issue of reflexivity, often referred to within case study research. Within the context of this study, the research quality standards that were applied include, credibility, trustworthiness, confirmability, reflexivity and dependability.

4.7.1 Credibility

Credibility is the extent to which one can have confidence in the *"truth"* of the findings (Lincoln and Guba, 1985). The question arises as to how this confidence can be established and, drawing on the literature on this topic, I suggest that confidence can be established if the research methods are clear and explicit, if there is prolonged engagement in the field, and if there is a robust means of member-checking. In this study, the process for data collection and the tools used both data collection is clearly identified. A detailed reflective diary was also maintained by the researcher over the course of the study. The process for undertaking this study is clearly delineated and all information relating to the cases was maintained in a case study data base. The process attached to all aspects of data analysis has been clearly identified.

Prolonged engagement requires the researcher to spend enough time in the field to ascertain the culture, social setting or phenomenon of interest. Whilst observational data was not formally collected as part of this study according to Sandelowski (2000) once a researcher is *"in the field"* they should consider anything they observe as data. At the outset, I spent considerable time with the PCP in each organisation, developing an understanding of each service and how it operates. Substantial time was spent in the field over the course of this study as all, bar two of the staff interviews were undertaken within the service where the person was employed.

In addition, all the case files had to be reviewed within each service and this involved spending on average 18 hours per case in each service. This afforded me the opportunity to develop a working knowledge of each service, its support structures and the staff working within each area.

This knowledge assisted me in understanding how each service supported people with an ID and their families and staff and assisted in the triangulation of information across multiple sites when undertaking the cross case analysis in this study. In addition, I had previously developed a working knowledge of the three services involved in this study due to my role as a lecturer and a researcher and my previous lengthy experience as a clinician in one of these services.

Member checking, or respondent validation was employed in this study and is an ongoing process throughout the research study (Sandelowski, 1993). In some instances, this occurred *"on the spot"* during the interview, where the researcher clarified a statement with the respondent during the interview to ensure the researcher was adequately understanding the point the respondent was making. The researcher's emerging themes and inferences were also fed back to staff and family members for verification. Family members were fed back to individually. Staff, in one organisation received feedback in the form of a focus group. This approach is not without its detractors who suggest that

> *"sometimes members are more interested in concrete descriptions of their own experiences than in abstract synthesis that incorporates them with other members' experiences"* (Sandelowski, 1993, p.5).

A response to this objection might be, that the converse could also be true, and that certain individuals might be more interested in how their experience compares to that of others, than being given a synopsis of their own story. In this study, the experiences of participants were amalgamated, and the focus group were presented with an overview of the cross-case analysis of the nine studies.

4.7.2 Trustworthiness

Trustworthiness or transferability involves showing that the findings have applicability in other contexts (Lincoln and Guba, 1985). Enough information needs to be provided to demonstrate that the findings and conclusions drawn can be applicable to other situations or populations. This perspective is not without its detractors who suggest that transferability or generalisability of qualitative research is impossible given that such projects are specific to a situation or person (Shenton, 2004). However, others including Stake (1995) and Lincoln and Guba, (1985) state that despite each being unique, individual case studies are an example of a broader group and have the potential to be transferable.

The use of multiple case study design is a mechanism to generalise from case study research according to Tight (2017) and can lead to the potential development of what is referred to by Jensen and Rodgers (2001) as the *'intellectual gold'* of case study research. Nonetheless, the issue of transferability in case study research must be approached with caution; key to this is ensuring that a thick description of the case is provided to ensure the reader has enough information to compare the case to other cases and situations, whilst protecting the anonymity of those involved. Thick description is advocated by many researchers such as Merriam, (1998), and Lincoln and Guba (1985, p.306) as a method to

> "*evaluate the extent to which the conclusions drawn are transferable to other times, settings, situations, and people"*.

In this study, much attention was paid to describing the cases in enough detail so as to ensure the reader understood the detail of each case and the context in which it occurred but mindful of the need to ensure the anonymity of those involved. In addition, thick descriptions ensure that

> *"anyone else interested in transferability has a base of information appropriate to the judgment"* (Lincoln and Guba, 1985, p. 124- 125).

The fact that nine case studies were undertaken as part of this study and a cross case analysis was also conducted also ensures the transferability of the findings of this study.

4.7.3 Confirmability

Confirmability is defined as a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest (Lincoln and Guba, 1985). As is the case in this study, the confirmability of findings is evident as findings are derived from a variety of different sources and methods, thus limiting researcher bias.

The development of a case study database also supports confirmability as it ensured that the progress of the case study, the development of findings from the data and the construction of each case story can be traced.

4.7.4 Reflexivity

Within the context of qualitative research, it must be acknowledged that the researcher is also, in and of him/herself, a research instrument. According to Stake (1995, p. 95), qualitative research champions the role of the researcher and the *'interaction of researcher and phenomena'*. The researcher is responsive to the individual context of each case, can adapt to changing circumstances during the research process, can pick up on non-verbal cues, can process data and summarize information as it evolves. The role of the researcher in case study research has often been likened to that of a detective, where the researcher is searching for all the pieces of a puzzle (Merriam, 2009).

The researcher as *"research instrument"* can be a positive influence on a study but it can also lead to the introduction of bias into a study. Therefore, a self-critical approach is required on behalf of the researcher, to manage potential bias.

Several studies have been undertaken which identify the importance of reflexivity in the management of subjectivity and researcher bias in qualitative research (Bourke, 2014; Bradbury Jones, 2007; Berger, 2013). Reflexivity refers to the process of unpacking the researcher's positionality within the research process, through self-reflection. Reflexivity can support the researcher in recognising how their positionality can both positively and negatively impact the research process and the findings of the studies that they undertake (Berger, 2013).

According to Malterud (2001), to ensure reflexivity, enough information must be available to understand the researcher's motivation for undertaking a piece of research. The researcher's background and perspectives and strategies must be developed to ensure that any issues that may arise due to a potential researcher bias are effectively dealt with during a study. Several strategies have been employed in this study to support reflexivity through all aspects of the study, through data collection, analysis and the development of findings, including the use of a reflective diary.

Developing a reflective diary affords the researcher the opportunity to explore researcher subjectivity (Bradbury-Jones, 2007). It is also recommended that the researcher explicitly identifies where their own subjectivity influenced the research process by providing examples of it. The concept of the subjective 'I' within a research context is explored by Peshkin (1988) who identified the need for researchers to explore their subjectivity and explicitly address its impact in terms of the researcher's bias, interests and personal values. Over the course of this study I was conscious of my role as a nurse, an educator, but also of my role as a parent and a sibling and how these roles impacted on the judgments I made over the course of the study. These perspectives were logged in my reflective diary and an example of a reflective piece from my diary is available in Appendix 19. From the outset, my role as a nurse and an educator was something which influenced the development of this study. I was conscious of my current role as an educator and how my presence in the clinical practise area might impact on my students and the mentors who supported them. I was conscious of the need to mediate against any negative impact on my students and their mentors, while in the clinical setting as a PhD student myself. This insight into my role as both "educator" and "student" influenced the research process from the start, beginning with my choice of methodology.

I was also conscious of being an "insider" as both a nurse with over 20 years of experience in the field of intellectual disability and in the case of one of the services, as a former employee. My level of experience and my connections within ID services, were beneficial in several ways. My connection with a number of services meant that staff within these services were aware of and were willing to engage with me and support me in accessing case files, families and staff as part of the research process. In addition, my years of experience also facilitated me to recognise the subtle nuances and differences between and within services, which informed my understanding of the findings of the study.

However, I also had to be conscious of the impact of my past experiences and my own professional standards when interpreting the findings of this study. I was aware to some extent of my pragmatic approach to life as an individual and as a nurse and became more conscious of this through my reflective diary and more so through my discussions and ongoing consultation with my supervisors. When initially undertaking the cross-case analysis of the nine cases in this study, I was very focused on discussing issues that had arisen and needed to be addressed across cases, which is of course important. However, during one discussion with my supervisors, one of my supervisors stated, *"there are a number of examples of very good practice here"*. This statement caused me to pause and reflect on the cases again, now conscious of the fact that my pragmatic, problem solving approach to nursing might cause me to overly focus on identifying where issues had arisen for the nine people involved, to the detriment of acknowledging the many examples of good practice also evident in the individual cases. Ongoing consultation with my supervisors assisted me in challenging my assumptions regarding the data and assisting me in guarding against potential bias arising from my own experiences as a nurse and lecturer in the field of ID, for over 20 years. The use of my reflective diary also assisted me in teasing out points made by my supervisors in relation to the individual cases and in the cross-case analysis.

I was also conscious of my role as a daughter, a sibling, and a friend within the context of having experienced bereavement a number of times prior to and during the PhD process. In appendix 19, I indicated that I found the case of Jennifer a difficult one to write and that I became emotional when trying to build the case. I was conscious, when listening to the recording of her sister Imelda of her level of distress and reflected on the distress I had experienced when supporting someone at end of life that I cared about. From a positive perspective, this empathy helped me to understand the depth of emotion expressed by Imelda. However, I was also conscious that I should not make assumptions about Imelda's bereavement in relation to losing her sister based on my experience of bereavement.

I had to listen to and reread Imelda's account many times and pay particularly close attention to her case, to ensure that I stayed true to her account of Jennifer's story and her own story.

Through the course of developing the cases I also came to recognise that I could be very impatient. While I happily took the time to build each person's story into an individual case, I was impatient during the cross-case analysis, feeling that I should be able to identify commonalities and differences between the cases more easily. This prompted discussions with my supervisors regarding *"forcing the data" into* a particular theme or category and required that I continue to reflect on the individual cases while undertaking the cross-case analysis, and go back to the individual interviews and transcripts to ensure that I was staying close to the original data and the views as expressed by the participants involved.

While the use of a reflective diary and discussions with my supervisors were the primary methods I used to remain conscious of my positionality within the research process, presenting the data at conferences also provided opportunities to pause and reflect on how I presented the data and my assumptions about the data, both in terms of reflecting on the data while putting together a presentation and reflecting on feedback and questions following presentations.

Overall, the reflexive process was essential to ensuring that I was conscious of the impact of my positionality in the research process from start to finish and in safeguarding against the slow creep of my own subjective biases into the findings of the study.

4.7.5 Dependability

Dependability involves showing that if a research study was repeated, in the same context, that the findings would be consistent and similar results would be achieved (Lincoln and Guba, 1985). This is more difficult to achieve in qualitative than quantitative research where one would be replicating a study *"in vivo"* in a natural environment as opposed to a controlled environment within a laboratory. Within the context of case study research, findings are context specific and the issue of dependability is closely linked to the processes developed in undertaking the research study. The level of detail provided should be enough to ensure that another researcher could replicate the study if required. In case study research an *"audit trail"* should be used to establish dependability. It should be possible for a researcher, not linked to the original study to be able to identify how data was collected, categorised and how conclusions were made. Detailed information as to how this study was undertaken, and how the findings were established has been provided within this study.

4.8 Ethical Considerations and Gaining Ethical Approval

When undertaking any form of research, ethical principles must be upheld to protect the rights of participants. Within the context of this study, specific consideration had to be given to the sensitive nature of the research topic i.e. end-of-life care and the fact that those being interviewed had been bereaved within the previous two years. In this section of the thesis, the ethical issues relating to this study are discussed and actions taken to uphold the rights of participants are explained.

Prior to commencing this study, the requisite ethical approval was sought and granted from the relevant Clinical Research Ethics Committee of University College Cork (see Appendix 3). Three organizations met the inclusion/exclusion criteria for the study and agreed to participate in the study. In addition, each of these organizations had their own Research Ethics Committee. Undertaking research in multi-centre sites can create significant challenges with respect to ethical approval (Landers, et al, 2012) as different organisations have individual application forms and approval processes which must be completed. This took considerable time both in completing the required ethical approval paperwork for each organisation and liaising with the Ethics Committee within each organisation. Ethical approval was granted by all three organizations.

One organization requested changes to the letter of introduction to be sent to family members. All three organizations insisted that no personal information regarding decedents or their family members be provided until family members had agreed to participate in the study. In addition, documentation could not be photocopied or removed from individual organisations or files. This stipulation was adhered to over the course of the study and as referred to in section 4.4 involved the transcription of information from the individual file into an individual notebook, identified for each case.

The ethical principles of beneficence, non-maleficence, respect for human dignity and justice are of fundamental importance and must be upheld during the research process (Polit and Beck, 2009; Dooley and McCarthy, 2012). This study was also informed by the guidance document developed by the Nursing and Midwifery Board of Ireland (2015) and by the Code of Research Conduct developed by University College Cork (2017).

4.8.1 Beneficence and non-maleficence

The ethical principle of beneficence requires that research should benefit either the individual involved in the study or society in general (Polit and Beck, 2009).

This principle was upheld in this study as participants were made aware that while the study would not directly benefit them personally the results of the study could inform developments in practice and potentially improve the quality of end-of-life care provided to people with an ID. This information was provided to participants in the information leaflet which was sent to all study participants.

While it was not envisaged at the outset of this study that participants would benefit personally from contributing to the study, most respondents were eager to talk about their loved one. The fact that some participants can value the opportunity to tell their stories has been identified in other studies relating to end-of-life care (Payne, 2007). In one instance, a letter was received from a research participant thanking me for the opportunity to talk about her experience. In another instance, a research participant who initially stated that making the decision to participate in the study had been very difficult for her, later stated that she was glad that she had done so and felt a *"weight was lifted".* With respect to the related principle of non-maleficence, or the obligation to avoid and prevent harm, it was considered that participants in this study were exposed to a minimum of risk as this study does not involve any form of invasive, therapeutic intervention. However, I was mindful that these participants could be viewed as a vulnerable population as they were recently bereaved. It was not possible to know in advance how each individual would respond to specific questions.

On the day of the interview, participants were again informed of the purpose of the study and asked if they wished to continue. Permission to record the interviews was gained from all participants and interviews were recorded on a digital recording device. Participants were assured they could stop the interview if they wished to do so. They were also informed that they could refuse to answer any question if they so wished. If participants became upset or tearful, each individual was asked if they wanted to take a break for a while, or postpone the interview until another date, or withdraw from the study. In some instances, participants wished to continue without taking a break, others opted to have some form of refreshment and engaged in general chit-chat with the researcher for a while and then returned to the topic when they were ready. All participants were given an information leaflet with information on counselling services. On many occasions research participants did become tearful and upset, at which point recording was paused, and support was provided. Therefore, several safeguards were put in place during the interview process to support individual participants as previously identified in section 4.4.

4.8.2 Respect for human dignity

Respecting human dignity requires that the researcher respects the individual participant's right to self-determination, and to uphold the principles of full disclosure and informed consent.

Individuals' rights to self-determination were upheld in this study as all potential participants were respected as autonomous human beings, who were free to choose to participate in the study or not. In this study, all participants were informed of the nature of the study and provided with an information leaflet detailing what would be required of them should they decide to participate. I also contacted potential participants by telephone, after they had posted their consent forms back to me and answered any questions. I then asked individual participants if they still wished to participate at this point, and then made appointments to meet them. When meeting individuals to conduct the interviews, I again asked participants if they wished to continue. Each participant signed a consent form, which detailed exactly what was required of participants during the study and recorded their consent to the researcher having access to the decedent's file.

4.8.3 Justice

The principle of justice requires that participants are treated fairly, and have their privacy protected. At all times participants were treated with respect, dignity and kindness. Deciding on venues for the interviews was always decided upon by the participant and breaks were provided as required during the interview process. When interviewing staff during work hours, I was mindful that staff had to prioritise the needs of service users. In some instances, interviews had to be rescheduled due to time constraints impacting on staff and I had to return at a later date.

Anonymity and confidentiality were ensured since each individual case and the participants associated with each case were assigned a code by the researcher. All raw data was secured in a locked filing cabinet, and a password protected computer. All raw data will be held in a secure manner for ten years as per Code of Research Conduct (University College Cork, 2017). The issue of anonymity required attention in this study as it is imperative that individual cases could not be identified.
Therefore, due diligence was paid to presenting the cases in such a manner as to ensure the services involved, the decedents and family and staff could not be identified either in the thesis itself or in any future publication or presentations.

Conclusion

In conclusion, the purpose of this research study is to describe and analyse end-of-life supports and decision making practices in specialist ID residential services. Case study research methods were deemed the most appropriate method to facilitate the exploration of the end-of-life care of people with an ID, as this approach would allow the presentation of highly detailed accounts of the end-of-life care of people with an ID.

Case study methodology, using multiple-embedded case study design is a complex methodological approach, drawing on a range of data sources and multiple perspectives including those of family members and professionals.

It required the development of a case study database which ensured all data relating to the study was collected and stored in a rigorous and organised manner.

The process of data collection was identified, exploring obstacles which needed to be overcome in gaining ethical approval and documentation across multiple sites. Data analysis strategies were also identified with clear guidance provided on how individual case studies were initially developed. The process of cross case analysis was then presented.

Strategies used to ensure rigour and trustworthiness in the research process were presented and issues relating to reflexivity and researcher bias were also addressed. The nine case studies which were developed as part of this thesis are presented in Chapter 5.

Chapter 5: Findings Chapter

Introduction

The overarching aim of this study is to describe and analyse end-of-life care supports and decision making practices in specialist ID residential services. This chapter presents the findings and it is comprised of two parts. Part A provides contextual information relating to the three organisations involved. It also provides demographic information relating to the nine decedents, and the families and staff who supported them. Part B of this chapter presents the nine case studies, which document the end-of-life care provided to the decedents, who are central to this study.

Part A: Contextual Organisational and Demographic Findings

As stated in Chapter Four, the context in which end-of-life care was provided was of fundamental importance in exploring the end-of-life care provided to people with an ID and the experiences of those supporting them. The provision of end-of-life care centred around (1) the decedents in this study (2) the ID service where the person was supported and (3) the families and staff supporting them.

Unless otherwise stated, data underpinning each case is drawn from the documentation contained in their case files such as nursing and medical notes, consultant and outpatient's reports, and discharge letters. With respect to qualitative comments, where **'S'** appears next to a quotation it denotes staff, **'F'** denotes family, and **'M'** denotes service manager. Where qualitative comments were retrieved from either the Quality of Death and Dying questionnaire (QODD) or the Staff Perceptions of End-of-life Care (SPELE), the acronyms used for each questionnaire are presented alongside the corresponding quote.

5.1 Contextual Organisational Findings

Part A of this chapter comprises of two distinct sections. Section 5.1 provides contextual information relating to the three ID organisations in this study. Section 5.2 provides demographic information in relation to the nine decedents in this study. Further demographic information is provided in relation to the individuals who encompass the *"circle of support"* around each individual decedent. In supporting the decedents involved, those within the circle of support accessed the support of health professionals in services external to the ID residential services including hospitals, hospices, community palliative care teams (CPCT)and GP services (See figure 6).

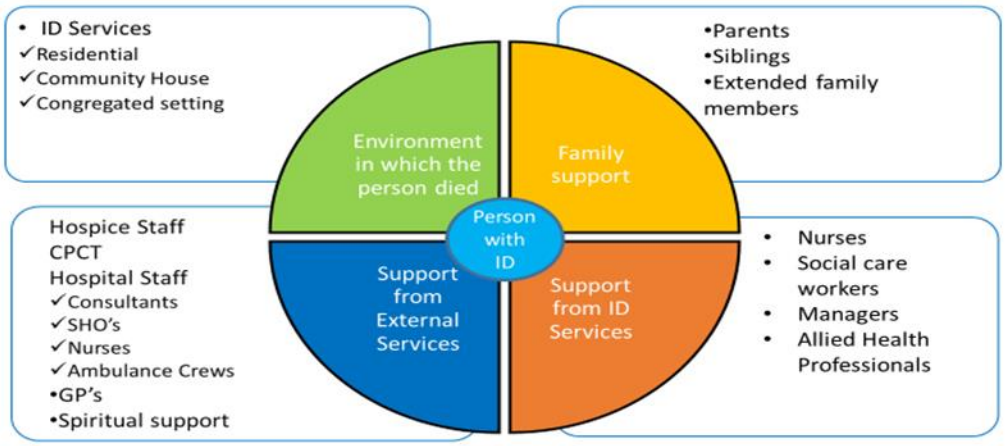


Figure 6: Context in which End-of-Life Care is provided

5.1.1 General organisational information

Having reviewed the mission statements of each organisation, it was evident that all organisations were committed to the provision of person centred services, which promote the rights of individuals and support people to achieve their full potential. The organisations also sought to facilitate service users in accessing and availing of services and activities within their own local communities. While all three organisations emphasized the importance of choice and advocacy, only one organisation made an explicit reference to the rights of service users to make and influence decisions.

All three organisations had provided services for people with an ID for decades ranging from between 60 to 80 years. These included day, community, residential and early intervention services, home and family support services, respite services, independent living, employment and recreational services. All organisations supported service users across the life span, in both urban and rural areas.

The nine individuals in this study were supported in several forms of residential care. Three individuals were supported in retirement homes, one in a community home and five were in community group homes. These services were in compliance with the National Standards for Residential Services for Children and Adults with Disabilities (HIQA, 2013) and had been in existence for over a decade within each organisation involved.

The form of residential care provided to these individuals would reflect the kind of residential care provided for people with an ID nationally. Statistics from the NIDD (Hourigan et al. 2017) indicate that of the 26.9% of people in receipt of full time residential care, 15.5% live in community homes and 11% live in some other form of residential care, indicating that, as seen in this study, the majority of people are cared for in community homes.

All organisations involved had access to a multi-disciplinary team including nurses, care assistants, occupational therapist (OT), speech and language therapists (SLT), psychologist, psychiatrists, GPs and pastoral care. Each organisation had links into the local hospital, hospice and CPCT.

5.1.2 Impact of an ageing population

Managers across all organisations reported that they were supporting an increasing number of older people and had specific residential services focused on meeting the needs of this population. However, these services did not have the capacity to meet organisational demand according to the managers interviewed.

> M3 *"We have ten we have twenty beds you could say for elder care whether that is due to age or medical reasons or whatever. I suppose the difficulty is now because we have an aging population, we don't have enough beds"* [89-92]

Two organisations were providing support for people with Down Syndrome and dementia who required significant resources which organisations struggled to provide. Despite the fact that service managers were increasingly supporting an ageing population, none of the organisations involved had developed or adopted an ageing or dementia strategy. Managers and staff within these organisations stated that the lack of a proactive strategy on ageing and dementia meant little future organisational planning was occurring.

> M5 *"The future [planning] isn't there, it's not there and I mean obviously the people in the community [services]will concur with that, there is no planning for them sure they are only waiting for the next somebody to die in [name of services] so they can be bought in".* [1,147-1,450]

These services required higher numbers of staff and managers identified the importance of getting the right skills mix in place. A lack of nursing staff was a particular issue within all organisations along with a lack of staff suitably qualified and experienced in end-of-life care. Managers stated that providing end-of-life care to those who needed it was resource intensive but indicated that requests for support were always positively responded to. However, one manager indicated that other areas within an organisation could suffer when resources had to be diverted to support the provision of end-of-life care. This manager further indicated that requests for additional funding resources had been turned down in some instances by the Health Service Executive (HSE).

> M1 *"Well it comes at a cost to the organisation because unfortunately while we have put some cases forward for funding [to the HSE] and it's not funded so there is some other part of the organisation suffering if you like or their service level is reduced."* [136-139]

In some instances, work practices changed to make more effective use of resources. For example, in one service, rostering practices were changed to provide additional supports at times identified by the staff involved. In another organisation, staff self-rostered and made sure that experienced members of staff who knew the individual who was dying well, were always available. While many services initially developed to provide supports for older people, they evolved to provide end-of-life care in many instances. This evolution led to further changes in the organisations involved, including organisational culture.

5.1.3 Organisational culture

The emergence of an ageing population within organisations, over the past three decades required services to adapt to the changing needs of services users. This caused a cultural shift within the organisations involved which, heretofore, had focused on facilitating people to be included in, and actively participate in, their own communities. Caring for an older generation meant that services had to develop in ways that were cognisant of the new and altered needs of this ageing population. As people aged and levels of ability changed, services had to modify the range of activities and supports provided. The focus of care changed from prioritising ongoing management and activation of individuals to the management of their changing and evolving health needs. It also required organisations to reach out to access support services, external to the organisations themselves, such as palliative care services.

Changing the cultural ethos and approach of a service to meet the changing needs of service users, could be difficult and took time. Services needed to change to ensure they could meet the more medicalised care needs of those involved.

> M3 *"They are applying the social care facilities, the social care model; the needs of the service users have changed since it [the service] opened and I need convert to [the service] you know… we can't get that [change] over the line".* [143-144]

While managers stated this cultural change was occurring, and organisations were adapting to meet the needs of older populations, both management and staff suggested there was still a hesitancy within organisations to explore and discuss end-of-life care.

5.1.4 Organisational policies and documentation

None of the organisations involved had specific policies relating to end-of-life or advance care planning or directives. All organisations were committed to the development of end-of-life/advance care planning policies and one organisation had a policy at draft stage. However, the manager involved in the development of this policy felt it was too generic and would need further work.

> M5 *"I think it is a very generic policy, if I'm honest, and not saying that we should be treated differently to everybody else, but I think it's not practical enough".* [463-465]

No reference was made by managers to the inclusion of members of the CPCT team or hospice personnel in the development of policies relating to end-of-life care or advance care planning within ID services.

All three organisations had individual service users with Do Not Resuscitate (DNR) or Not for Resuscitation Orders (NFR) in place, and all had distinctive approaches for documenting these orders. In two organisations such orders took the form of a handwritten letter stating that the individual was not for resuscitation and the letter was then signed by both the GP and the family. These letters did not elaborate on the medical condition of the person involved, give details as to how the decision not to resuscitate was made, or indicate if the person involved had been informed of, or consulted about, this decision. In one of the organisations, the manager involved indicated that families no longer signed these letters. These letters were now written and signed by the GP and witnessed by a member of staff although family members continue to be consulted. The third organisation had a specific *"Do Not Resuscitate Form"* that was completed and signed by the GP. This document took the form of a checklist where the reasons for taking the decision not to resuscitate were documented. Family members were not required to sign the form but there was a section to indicate if they had been informed, and whether the person with the ID had been informed or not and, if not, why not.

All organisations had an end-of-life form, as part of their administrative process, for those in residential care. This end-of-life form did not make reference to the person's wishes or perspectives in relation to end-of-life care or those of their families. This form documented information in relation to religious beliefs and funeral arrangements. The form in one organisation, required detailed information in relation to the undertaker to be used and the financing of the funeral.

These end-of-life forms were completed routinely with family members, not with the person with the ID. In two organisations these forms were routinely completed for those in residential care. However, one manager in the third service indicated that these end-of-life forms were not used consistently in all services. This manager stated:

> M4 *"I know that in the wider service they kind of laugh a little bit in the wider service about us with those forms and having our end of life things done".* [414-416]

Apart from these specific forms, aspects of the end-of-life care of people with an ID were identified and documented in person-centred plans and in nursing notes. The input of GPs was documented in medical notes and interactions with consultants were evidenced in letters from consultants. Each of the three organisations had different approaches to documenting person-centred care, nursing, and medical care.

5.2 Demographic Data

This section presents demographic data relating to the decedent's themselves and their individual circles of support. These circles of support were comprised of families and staff, integral to the end-of-life journey of each individual in this study.

5.2.1 Decedents

This study centers around nine individuals, Jennifer, Johnny, Finbarr, Charles, Frank, Louise, Joanne, William and Arthur (pseudonyms). An overview of the pertinent demographic and health related data of these individuals is presented in Table 2. Six of these individuals are male and three are female. Six of these individuals had Down Syndrome, one had an Acquired Brain Injury, one had a neurodegenerative condition, and one had a developmental delay of unknown origin. Three were initially classified as having a mild level of ID, two had a moderate ID, and four had a severe level of ID. Evidence of cognitive decline was identified in all individuals in the two years prior to their deaths. Two individuals, initially classified as having a mild ID, were reclassified as having a severe level of ID, such was the level of cognitive decline in the last two years of life. The youngest decedent died at the age of 41, the oldest was 86 and the average age of death was 60. Of the nine decedents, the average number of years spent in residential services was 37. The shortest stay was seven months, and the longest was 73 years. This demographic pattern is consistent with statistics from the NIDD (Hourigan et al. 2017) which identified that 82% (n=6,201) of those availing of residential services in Ireland have a moderate to severe level of ID, and 86.7% (n=6,530) are over the age of 35.

Each individual presented with co-morbid health conditions, the minimum number was three and the maximum number was 13. On average, each decedent had nine co-morbid health conditions. Of the six individuals who had Down syndrome, three had been diagnosed with Dementia and four had epilepsy. Cardiac and respiratory conditions were also evident in six of the nine decedents. Four of the nine decedents had a mental health condition, including depression, anxiety, psychotic episodes and obsessive-compulsive disorder. The diagnosis of these conditions occurred at varying points across the life trajectory, ranging from a maximum of five years prior to death.

The cause of death in two cases could not be determined as their death certificates were not available. Cause of death in four cases, was aspiration pneumonia, with end-stage dementia, organ failure and cardio-respiratory failure accounting for the deaths of the remaining individuals.

Overall, the nine individuals identified in this study could be considered typical of people with an ID availing of residential services in Ireland. They were all over the age of 35, with varying levels of capacity. All of these individuals presented with comorbid health conditions frequently found in this population. The cause of death of these individuals was in keeping with those commonly associated with this population.

5.2.2 Family participants

Ten family members were interviewed, and all interviewees were female. In nine of the cases, these women were siblings of the decedent and, in one case, a sister-in law was interviewed. In two cases, parents of decedents were alive at the time of the study. However, these parents were at an advanced age, with significant health issues and their care giving role had been taken over by other family members, who were interviewed as part of the study.

Table 2 Demographic and health information relating to decedents

Case	1 Jennifer	2 Johnny	3 Finbarr	4 Charles	5 Frank	6 Louise	7 Joanne	8 William	9 Arthur
Sex	Female	Male	Male	Male	Male	Female	Female	Male	Male
Level of ID	Mild to Moderate	Severe	Severe	Severe	Mild	Moderate	Moderate	Moderate to Severe	Mild to moderate
Cause of ID	Neurodegenerative condition (late diagnosis)	Acquired Brain Injury	Down Syndrome	Down Syndrome	Develop-mental delay of unknown origin	Down Syndrome	Down syndrome	Down syndrome	Down syndrome
Cognitive decline in 2 years before death	Declined to severe level of disability	Yes	Yes	Yes	Yes	Yes	Declined to severe level of disability	Yes	Declined to moderate to severe disability
Number of years in residential care	26	32	39	47 years, moved service 2 years and 9 months before death	73	5	8 years, moved service 8 months before death	4	3

Case	1 Jennifer	2 Johnny	3 Finbarr	4 Charles	5 Frank	6 Louise	7 Joanne	8 William	9 Arthur
Access to hospice/CPCT	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Age at death	41	78	61	51	86	63	50	56	55
Cause of death	Aspiration pneumonia Degenerative neurological condition	End stage dementia Vascular dementia Urinary tract infection Epilepsy	Pneumonia Dementia	Multiple organ failure End stage Alzheimer's disease Down Syndrome Epilepsy Hypo-thyroidism	Cardio-respiratory failure Transient Ischaemic Attack Hyperten-sion	Death cert not available	Aspiration pneumonia - linked to Dementia, Respiratory failure	Death cert not available	Aspiration pneumonia Recurring aspirates due to dementia Respiratory failure
Place of death	Hospice	ID service	Hospital	ID service	Hospital	ID service	ID service	ID service	ID services
ID recorded on death cert	No	No	Yes	Yes	No	As above	No	As above	No

5.2.3 ID services staff

A total of 16 staff, 14 women and two men, were interviewed. Ten of these staff were nurses who directly provided end-of-life care to the individuals involved, one was a day service supervisor, who also continued to support the person at end of life (see Table 3). Of the eleven staff, seven were ID nurses, one was a general nurse, one was a psychiatric nurse and one was dual qualified, with both a general and psychiatric qualification. These respondents had varying degrees of experience in ID settings, the minimum number of years was seven, the maximum was forty, with respondents having, on average, twenty-eight years of experience. Seven of these eleven respondents had some form of education in end-of-life care (see Table 3). However, the level of training varied greatly with the majority having accessed one day or half day courses in the local hospice. One staff member had a Postgraduate Diploma in Palliative Care while another two had completed a Postgraduate Diploma in Gerontology.

Table 3: Demographic information relating to frontline staff

Role	Qualification	Service	Specific education in end- of-life care
Staff Nurse	RNID	7	Postgraduate Diploma in Palliative care
Staff Nurse	RNID	30	Post Graduate Diploma in Gerontology
Staff Nurse	RNID	36	Post Graduate Diploma in Gerontology
Staff Nurse	RGN/RPN	34	Palliative Care Course provided by local hospice
Staff Nurse	RNID	30	None
Staff Nurse	RNID	30	Half day training course provided by local hospice
Staff Nurse	RNID	23	1 day course on syringe driver management
Staff nurse	RGN	27	1 day course on advance care planning
Staff Nurse	RNID	25	Day courses on palliative care (not specified)
Staff Nurse	RPN	40	None
Supervisor	Artist	24	None

The remaining five respondents were service managers, and all held a nursing qualification also but did not provide direct, hands-on nursing care. Years of experience ranged from seven to thirty-four years. Two managers had a postgraduate diploma in gerontology, and one had a postgraduate diploma in palliative care.

Conclusion

Part A of this finding chapter presented contextual and demographic information relating to the organisations involved, the decedents themselves, family members and staff. All organisations involved, had provided services to people with an ID for decades and adhered to the National Standards for Residential Services for Children and Adults with Disabilities (2013).

These standards stipulate that services must have a staff culture that promulgates and implements person centred practices to promote the rights and dignity of service users. The fact that the services involved in this study were certified by HIQA speaks to the quality of the services involved.

Having reviewed organisational documentation, it is evident that the three organisations in this study had a cultural ethos focused on the provision of person centred services which promoted the inclusion and independence of people with an ID within their own local communities. All these organisations had robust person centred planning policies and processes which focused on disparate aspects of person centred care. This including the physical care of the individual, psychological and psychiatric support, promoting activation and integration, providing social support and identifying the wills and preferences of service users.

All organisations had to adhere to national policies and legislation. Currently these organisations, are changing the way residential services are provided, moving people from large congregated settings to small community homes, in keeping with the requirements of a national policy of decongregation (HSE, 2011). All the service managers interviewed indicated that these organisations were adjusting to supporting an emerging older person population within these services. This involved providing appropriate residential services and support staff. All service managers indicated that they struggled to provide enough services to meet the demands of an emerging older population.

None of the organisations involved had developed or adopted an ageing or dementia strategy. It was evident that service managers and staff were committed to supporting an aging population. However, in the absence of clear strategies and funding to support these services, service development occurred in an ad-hoc manner. While managers accommodated as many people as possible, they were clear that they could not provide supports to all those who required them.

The provision of end-of-life care within these organisations, developed from the establishment of care of the elderly services. While no definitive policy was available within the organisations in relation to end-of-life care and advance care planning, all organisations had a policy at draft stage at the point of data collection for this study. Despite the lack of polices, all managers and staff involved, worked to effect the changes required to provide end-of-life care to individuals who required it. The provision of end-of-life care required a cultural shift within the services involved who heretofore had focused on a social model of care. As the health needs of individuals changed and co-morbid health needs increased, a change in the focus of care of individuals was needed and a greater level of medical intervention was required.

Once again, service managers and staff worked to meet the changing needs of the service users they supported and to provide them with appropriate end-of-life care. Staff reached out to access the specialist skills set of hospices and CPCTs. Several staff furthered their own education in end-of-life care.

All organisations had a mechanism for recording NFR orders. End-of-life forms did document the religious beliefs of people with an ID and funeral arrangements of individuals. In keeping with the person centred ethos of these organisations, staff reported that resources were made available when required to support service users at end of life. However, managers noted that providing these resources impacted on other aspects of service provision.

Nine individuals with an ID who had died, were identified in this study. Six of these individuals died in ID services, two died in hospital and one died in a hospice, indicating that, in most cases, ID residential services were capable of and committed to providing end-of-life care. These individuals had been supported in ID services, on average for 27 years. Therefore, in many cases, staff within these services had established relationships with these individuals for the entirety of their adult lives. In other cases, individuals came into residential care at times of crisis, following a deterioration in their health, or that of a family member, or, having been hospitalized. Therefore, services were required to respond to the needs of individuals at end of life, where in some cases, they had a vast amount of knowledge about the person and, in other cases, limited knowledge with which to identify their care needs.

All of those identified in this study had experienced some form of cognitive decline in their last two years of life and had, on average, nine co-morbid health conditions. Therefore, the increased care needs of these individuals, required the availability of a multidisciplinary team which could meet their needs and services which were fit for purpose. In addition, the fact that each individual experienced cognitive decline in the two years prior to death, meant that opportunities to make decisions with them might have been lost, in the absence of advance care planning processes.

These decedents were supported by a wide range of individuals who formed a circle of support around each person. With respect to familial support, all respondents were female. In one case the respondent was a sister-in-law. In all other cases, respondents were sisters of the individuals involved. All family members had maintained contact with their sibling throughout their lives. In some instances, the decedents were in residential care from school going age and therefore family members did not experience them growing up in the family home. In other cases, these respondents were raised along with their sibling in the family home and were heavily involved in all aspects of their lives until they went to residential care.

The minimum number of professionals supporting each individual was nine, the maximum was thirteen. In the main, staff within ID services supporting individuals at end of life were registered nurses, although a wide variety of members of the multidisciplinary team were also involved. In many cases, these staff had supported the same individual for decades, in other instances these staff had a limited opportunity to get to the know the person involved. Management and staff within ID services had established links with other services and professionals outside of the organisations for whom they worked. These included GP, hospital and hospice support services as well as the CPCT. Access to these services was instrumental to supporting ID organisations to provide end-of-life care.

Having presented the contextual and demographic information relating to the organisations, the decedents, and those who encompassed individual circles of support, the individual case studies are presented in Part B of this chapter.

Part B: Case Studies

Part B of this chapter documents the nine case studies developed from multiple sources of data identified in this study. The case studies include family and staff members' perspectives on the end-of-life care provided to the decedent. Data relating to decisions made and the extent to which the decedents were involved in making decisions is also included in each case.

5.3 Introduction to the Case Studies

In each case, a brief introduction to the decedent is made, followed by a synopsis of the end-of life care provided to them. Each case presents an overview of the decedent's final two years of life, from initial changes in their health status, through to significant changes in their focus of care. This is followed by a description of their transition to end-of-life care and their final days.

Within the context of each case, initial changes in the focus of care of individuals are identified as a point in the person's life where additional supports were needed to ensure that they could continue to engage in day-to-day activity. The point of transitioning to end-of-life care was identified as the point when the person could no longer engage in their normal level of day-to-day activity and required on-going care. The person's final days are then documented.

5.3.1 Case study 1: Jennifer

Jennifer had a moderate ID and lived in a community group home for most of her life. Over the years, as Jennifer aged, her health and level of ability began to deteriorate until she died at the age of forty-one. Her sisters, Lorraine and Imelda, along with several professionals were integral to her *"Circle of Support"* (see Figure 7).

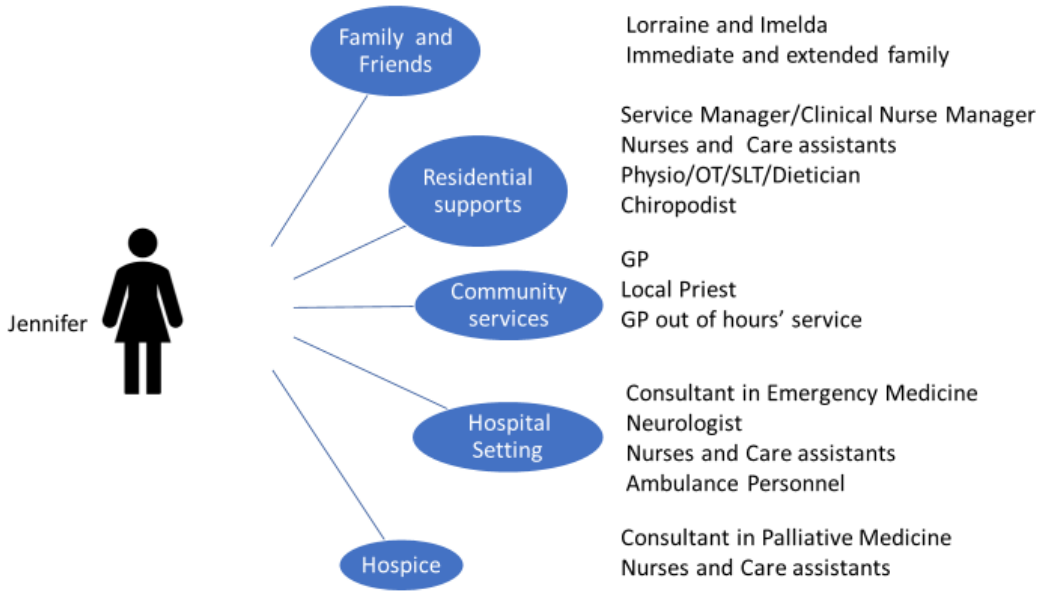


Figure 7: Jennifer's Circle of Support

Jennifer had physical and mental health conditions which were well managed in conjunction with hospital and community services. Four years before she died, Jennifer was diagnosed with a progressive central nervous system disorder and her level of ID increased from mild to moderate in the years preceding her death. This diagnosis had an impact on both Jennifer's family and staff supporting her. Her sisters when interviewed recounted how several potential diagnoses were made when she was young, with no definitive answers, until later in her life. Her sisters felt that her issues were wrongly linked to her mental health issues.

> F1: "*Like they were putting it down to mental health weren't they, but it wasn't like, it wasn't, it really wasn't, and there was nothing done, there was no scans done for Jennifer".* [631-634]

ID staff, when interviewed, also felt that Jennifer had gotten a "*raw deal"* and that diagnostic overshadowing where people assumed all her health issues had a mental health basis, had changed the trajectory of her life.

S1: "M*aybe because of the medication that she was on from a very early age like we never got to know the real Jennifer, you know it was almost like she was suppressed and so I suppose I struggled a little bit with that as well and it is sad when you think back it's just a pity that people weren't more clued in to you know genetic disorders".* [50-58]

5.3.1.1 Change in health status

Prior to her death, Jennifer's expressive communication ability deteriorated but those who knew her well could communicate effectively with her and her receptive communication was good. Despite the health conditions she experienced, the normal rhythm of her life continued, up to a month before she died. Both staff and her family indicated that her rate of decline was gradual given her degenerative condition. Staff, while acknowledging that the service was just beginning to grapple with providing end-of-life care, felt that more could have been done to prepare for Jennifer's deterioration.

S1: "We have taken a back seat with the advanced care planning and…… that does my head in. I just don't get that; I don't get why we wait…. so, let's talk about this now, let's plan for this now". [471-492]

Just over a month before she died, Jennifer was in good form and enjoying social outings according to the nursing notes. It was documented that she had a chesty cough and was treated with Combivent[2] nebs. Staff requested she be reviewed by the GP and since Jennifer became very chesty during the night, the GP out of hours' service was contacted and advised that Jennifer be admitted to hospital for IV antibiotics.

5.3.1.2 Change in focus of care

Once admitted, Jennifer was diagnosed with pneumonia, and commenced on IV antibiotics and fluids. She appeared lethargic but that evening she was reported in the nursing notes to be in better form. She was transferred to a ward where she appeared settled and relaxed. The following day, twenty-eight days before she died, Jennifer became unwell, her respiration rate increased and her O_2 saturation levels dropped. Her family were contacted, and it was agreed that staff from the ID organisation would provide cover for Jennifer in hospital on a formal basis. Thus, staff were rostered on duty in the hospital, to support her. She remained stable for the day, was more alert and seemed to have more energy that evening.

[2] For the management of reversible bronchospasm associated with obstructive airway diseases in patients who require more than a single bronchodilator. https://www.medicines.org.uk/emc/product/1423/smpc [accessed on the 6/9/2018]

Jennifer spent a total of twenty-three days in hospital before she died. During the first five days Jennifer was described as comfortable but unwell in the nursing notes. She was visited by the priest from the community home who knew her and was given a special blessing. During this period, both the family and staff from the ID service indicated that the hospital care provided to Jennifer was good. Jennifer's family rated her quality of end-of-life care as 10/10 (almost perfect) in the QODD while staff described her care as excellent, giving a score of 5, which is the highest score available in the SPELE. At this point, Jennifer had several symptoms that required management, according to data from the SPELE and QODD questionnaires. Both staff and the family did not think her pain was initially well managed but that it was brought under control as her medication was appropriately adjusted. According to the nursing notes, Jennifer experienced shortness of breath and copious respiratory secretions, however her medication and treatment was adjusted to combat this. While acknowledging the standard of care provided to Jennifer was good, her family stated that some nurses and doctors had never heard of Jennifer's degenerative condition. Other members of the family had this diagnosis and the family were aware of the trajectory of the disorder and its impact on the individual but felt that they were not always listened to:

> F1: "W*hen you try to talk to someone, they didn't know and I said sure I'll tell you if you want, and this is going to happen now next, they'd look at us like that and they'd look at one another and we would say we are not overstepping ye, we are trying to explain to ye what we saw in [other family member] and Jennifer would go the very same way".* [305-314].

5.3.1.3 Transitioning to end-of-life care

Eighteen days before she died, Jennifer's condition deteriorated, and a meeting was held between the family and the medical staff. Staff from the ID service were not included, nor was Jennifer. Jennifer had, at this point, received continuous treatment for pneumonia but was not improving, so treatment was withdrawn, and Jennifer commenced on comfort care.

> F1: "S*o we just decided then to stop everything. just stop everything because she wasn't coming back from it. What was going to happen to her, she wasn't going to get up and walk, she wasn't going to talk ever again".* [736-743]

Jennifer was moved to a single room in the hospital and commenced on a syringe driver. She was described in the nursing notes as comfortable and sleeping a lot. She remained chesty and had pyrexia[3] intermittently.

[3] Raised temperature. https://www.merriam-webster.com/dictionary/pyrexia [accessed on the 6/9/2018]

At this point, there was some discussion about commencing Jennifer on Percutaneous Endoscopic Gastrostomy (PEG) feeding[4] but she was too weak to have the procedure done. For the next four days Jennifer appeared brighter and she was taking sips of water and a small amount of yogurt but continued to be chesty and had pyrexia at intervals. Another meeting was held between the family and the medical team and according to the nursing notes it was decided that Jennifer should not have a PEG inserted and should continue with comfort measures.

During these days, Jennifer's family were with her every day. Most hospital staff encouraged them to stay with Jennifer as much as they wanted. However, on one occasion, a staff nurse told the family that Jennifer could be lingering for days and they couldn't be there all the time. According to her sisters, this conversation occurred in front of Jennifer, who became distressed at the thought that the family, particularly her mother, would not be there.

> F1: "*Jennifer was looking at us that time when she told us to leave, like a child now, being told your parents have to go and they are looking at you as if to say don't go so it was kind of frightening for her as well like".* [806-811]

When interviewed, both staff and family members indicated that Jennifer was frightened in hospital and needed reassurance from those who knew her well. These findings were also confirmed by data in response to the SPELE and the QODD. Her family felt that some staff in the hospital did not know how to communicate with Jennifer and failed to recognise her level of receptive communication and that she could understand much of what was said in front of her. The ID staff acknowledged that you had to be cognisant of the fact that Jennifer had an ID and adjust your communication style to hers and that only those who knew her well would pick up on her non-verbal cues:

> *S1: "There were times as well when she expected you to pick on the fact that you needed to say something or explain something you know, the look she had, the most amazing looks you know".* [594-596]

The family too acknowledged that staff in the hospital setting might need supports in this area;

[4] Percutaneous endoscopic gastrostomy (PEG) is an endoscopic medical procedure in which a tube (PEG tube) is passed into a patient's stomach through the abdominal wall, most commonly to provide a means of feeding when oral intake is not adequate (for example, because of dysphagia or sedation). https://www.asge.org/home/for-patients/patient-information/understanding-peg [accessed on the 6/9/2018]

F1: "*There should be someone there that understands more about these people whether they be young or old, they need to bring it into the system, they need it there, you know what I mean, you know, because the nurses were telling me afterwards 'we don't have time for this' and they don't".* [759-764]

At this point, her sisters were telling Jennifer she was sick but did not tell her she was dying. When the family spoke to her about how sick she was, she would respond that she was worried about her mother.

F1: "W*e would say, 'you are very very sick Jennifer you know, and she'd say, 'No, I am just worried about mammy'. Jennifer was like a child, she just worried about mammy and I would say, 'Jennifer, mam is grand, we are grand'".* [405-408]

ID staff, who supported her in hospital, indicated that Jennifer would raise the issue of how sick she was with certain staff but would then divert the conversation away from the subject again. Staff from the ID service indicated that these conversations occurred early in the morning or late in the evening just as staff from the ID service, were coming on and off duty, in the hospital.

S1: "I don't know if she was more vulnerable at those times, was there a fear of the change of shifts, was she afraid she wouldn't see that person again. I am not quite sure what she was thinking but that's when I felt she was most vulnerable and that's when she would ask specific questions in relation to how she was doing, she knew she was unwell". [100-105]

At this time, staff from the ID service indicated they would answer her questions as best they could, but that Jennifer would then become quiet after these conversations. Staff were conscious of her level of understanding when trying to provide her with open and honest answers. At times staff felt that Jennifer appeared to be aware of what was happening and then at other times did not seem to know. From the interviews and feedback from questionnaires, neither her family nor ID staff felt that they could say for definite that she understood she was dying. Staff did not want to offer an opinion on the level of acceptance, insight and control she had over her death and dying experience and felt the question was difficult to answer without being presumptuous. Staff could not speculate if her wishes and spiritual needs were met as stated in the SPELE but did believe that her religious beliefs were fully acknowledged.

5.3.1.4 The Final days

Seven days before Jennifer died, the staff from the ID service were awaiting a discharge care plan following the medical team's consultation with family. However, it was decided by her family, that Jennifer should be transferred to the local hospice and she was transferred four days later.

At this point, a significant difference of opinion arose between the staff from the community home and the family. While acknowledging that at the time, the organisation was just beginning to move towards providing end-of-life care, the staff felt they could adequately support Jennifer, in the familiar environment of the community group home.

The family, however, decided that Jennifer should go to the local hospice as the community home was further away from the family home than the hospice, making it more difficult for the family to be with her. The family were also aware that the community home was only beginning to provide end of life support and were worried the service would not meet Jennifer's needs. Staff acknowledged these concerns but felt that the family were making this decision under duress without being fully aware of what the service could offer. Staff indicated that while there was an opportunity for families to make their wishes about funeral arrangements etc. in advance there was no opportunity to engage in advance care planning.

> S1: "*Families should also be given the opportunity and should be encouraged to attend any pertinent meetings about end-of-life care (normally sign a form which only incorporates funeral arrangements and costs - so it's lacking an advanced care plan)".* [qualitative feedback from SPELE]

However, the staff did understand the family's decision and acknowledged that they probably did get to spend time with Jennifer in the hospice that they might not have had in the community home. The family said they were not sure exactly what Jennifer wanted and did acknowledge that the community home was her home and that staff there had played a significant role in her life. However, the family held the view that Jennifer was anxious to be with her mother and the best way to facilitate this was to have Jennifer in the hospice. Her sister acknowledged that moving Jennifer to the hospice was a difficult decision for them but believed they had made the right decision.

> *F1; "She thought she was going home, [to the residential home] and I was saying no, you are going to another hospital Jennifer, you know, she kind of got a bit sad, she thought she was going home".* [586-590]

On being transferred to the hospice, three days before she died, her condition was described as weak and deteriorating. She continued to be visited by staff from the community home, but they were not formally rostered for duty in the hospice. Jennifer remained on a syringe driver for the next three days and passed away peacefully in the presence of her family.

5.3.2 Case study 2: Johnny

Johnny had a severe ID and lived with his family until he was admitted to a community group home setting on a phased basis. As Johnny aged, his health and level of ability deteriorated until he died at the age of seventy-eight. His sister Helen, along with several other professionals was integral to his *"Circle of Support"* (see Figure 8).

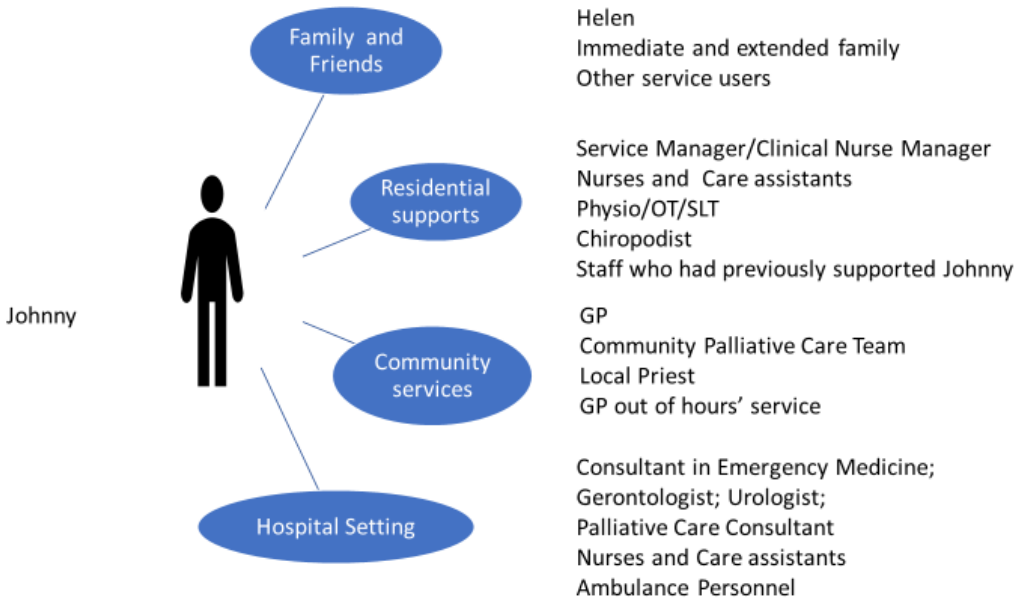


Figure 8: Johnny's Circle of Support

Johnny used a wheelchair in his final two years, was incontinent, prone to pressure sores and needed complete assistance with his daily care. His ability to eat deteriorated as he had issues swallowing.

5.3.2.1 Change in health status

Both Helen and ID staff stated symptoms of decline were present for two years before Johnny died. He was referred to a geriatrician who stated in a report sent to the community home, that his decline was consistent with advancing dementia, or a queried underlying malignant process. However, due to his "*fragile state"* further invasive procedures were not advised. He was diagnosed with dementia and, while aware of this diagnosis, Helen did not seem to fully understand it.

> F2: "*to me dementia is a very grey, I don't understand dementia, is dementia that you don't recognise people or that you are physically deteriorating"?* [200-203]

Following diagnosis, it was documented in his nursing notes that the GP and Helen decided Johnny would be cared for in the community home.

Details of this discussion were not provided in the medical notes, but the nursing notes stated the family were informed that Johnny might deteriorate within six months. No specific discussions about his long-term management took place at this time as according to staff, issues were dealt with as they arose.

Both the nurse and Helen when interviewed, stated that Johnny was not included in discussions as he lacked the capacity to understand the issues facing him. Johnny had periods of being relatively well and then unwell and staff focused on maintaining the natural rhythm of his life. He attended his day service, socialised, and went to family events until six months before he died. Staff felt that the family were lulled into a false sense of security since Johnny had remained well for over a year after being informed by the GP that he might decline within six months. Therefore, when Johnny began to deteriorate again, it came as a shock to them.

> S2: "*Every day they were getting they were delighted and a year and a year and a half, I'd say they thought they were nearly lulled into a bit of security, now everything is grand here. […] so, when things did happen then it was a big shock again*". [374-379]

5.3.2.2 Change in focus of care

During his final six months Johnny was hospitalized twice, and had over 20 GP visits, increasing in frequency in his final days. He experienced co-morbid health issues including gagging after eating, constipation, poor food and fluid intake leading to dehydration, poor skin integrity and frequent urinary tracts infections (UTI).

Two months before he died, Johnny was diagnosed with a UTI and commenced on antibiotics. On this day, he was reluctant to take fluids, and his speech was slurred. He aspirated while drinking and required suctioning. He was referred to A&E by the GP and was diagnosed with sepsis, dehydration and a UTI. Staff stated they had to push for this admission and did not view Johnny as needing palliative care at this point. However, they felt they could not manage him within the community home as he needed IV fluids;

> S2: "*I said we can't manage him here like this we can't, he can't be here because we couldn't, and he wasn't at that palliative end either so and as it turned out he was admitted and sorted out for a couple of weeks".* [383-385].

Johnny commenced on IV antibiotics and fluids, was catheterised, and referred for a SLT assessment. He was discharged nine days later and referred to a urologist. The GP subsequently reviewed Johnny's discharge plan with the service manager of the community home.

The plan was accompanied by a handwritten note, handed to the ambulance crew by a staff member on discharge from hospital, stating that he was not for resuscitation. The ID staff could not establish who had made this decision, it had not been discussed with them and the family had not been consulted.

The service manager, having been made aware of the note described this situation as *"extraordinary".* The GP determined that the note was to be ignored until he/she had a full discussion with the family, scheduled for the following week.

5.2.2.3 Transitioning to end-of-life care

It was agreed with the GP and documented in the nursing and medical notes that 1,000 mls of fluid would be an adequate daily fluid intake for Johnny. If he were to deteriorate or his fluid intake should fall below 1,000mls, staff were instructed to contact the GP out of hours' service and the GP left a referral letter if Johnny needed to go to hospital again. This was explained to the family. Staff persisted in their efforts to encourage him to take fluids. However, the nursing notes show, he consistently refused fluids, pushing the spoon away and pursing his lips. He was also pulling at his catheter and blood and protein were evident in his urine. Seven days after discharge, Johnny was reviewed by the GP, a UTI was diagnosed, and, according to the medical notes, he commenced on oral antibiotics. The GP met with a family member to discuss his NFR status but as another family member could not attend the meeting, he remained for full resuscitation, as documented in the nursing notes.

Over the following five days, Johnny became weaker, refusing all food and fluids. The GP out of hours' service was contacted and Johnny was admitted to A&E with recurring dehydration, hypernocturia and a UTI. Community home staff felt that the hospital staff were surprised to see him back again.

> S2: "*Very much the sense we got is oh what is this man doing here. We said we don't [don't know what you mean], you know, that he is managed at home. He went in because he was acutely dehydrated, and I think that really, really, it hit us very much, you know he is unwell we didn't realise that you really didn't want to see him again".* [262-267]

He was commenced on IV antibiotics and fluids that night and remained in A & E where he was reviewed by the hospital and the palliative care team. He was discharged the following day having been referred to the CPCT. The senior house officer (SHO) met with Johnny's family and explained the aim of symptomatic comfort care. The SHO indicated that he was to be encouraged to take fluids orally and the CPCT would support him in the community. An NFR order was put in place, following consultation with the family and the SHO according to his discharge record.

5.3.2.4 The Final days

Johnny returned to the community home setting and was bright and chatty but took minimal fluids throughout the day. From information retrieved from the QODD and SPELE questionnaires staff could not speculate if he was frightened or at peace with dying, although Helen thought he seemed to be aware something was happening to him but was unsure as to what. Staff felt that he had little insight, acceptance or control over his own death and dying experience but felt that he lacked the capacity to be aware of these issues. During the interview, staff stated that Johnny's end came quickly and caught them off guard as it did not reflect their experience of supporting people with dementia at end of life. The following day, Johnny took little food and fluids, he vomited during the night and appeared restless. Staff documented that he was in pain in the nursing notes and expressed surprise when interviewed, that he was in so much pain. From their experience of caring for Johnny, they believed he had a high pain threshold. They had formed this belief based on an incident, several years earlier, where he suffered a significant injury but needed a minimal dose of analgesics, while recovering.

> S2: "*He never complained of pain and that particular night he could not settle, he was moaning he was groaning, and it wasn't that he was over stimulated".* [93-96]

According to the medical notes, the GP out of hours' service was contacted and he was prescribed analgesics. His family were informed of his condition and pastoral care was provided by the local priest. He was visited by the CPCT and commenced on a syringe driver. He was comfortable until that evening when his breathing became laboured. Oral secretions containing significant amounts of blood were observed and he appeared uncomfortable.

> S2: "*It was extremely difficult for us then to manage. So, it was yeah, we had a lot of secretions, oh my god, it was awful. It was awful there was just no end to it. And from our end we were just terrified he was going to bleed out".* [117-127]

Medication was administered as per the advice of the CPCT and the secretions reduced. His breathing became laboured during the night and at 3.30 am the CPCT was again contacted for advice and medication administered accordingly. At this point oral secretions containing large amounts of blood were a significant issue and staff were unprepared for this. His family were aware that he was distressed and wanted it to end for him.

> F2: "*I was really praying to god to take him rather than let him be because he just couldn't take any more of him. […]. he got, you see we didn't know what was wrong with him, but you could tell that he was suffering. And his eyes were literally bulging at one stage".* [253-269]

Staff managed his symptoms, using medication and suctioning with the support of the CPCT. Helen was aware that staff were in contact with the CPCT and could see the staff were trying to make Johnny as comfortable as possible. The family were involved in his care and tried to comfort and soothe him as much as possible. Helen indicated that there was a song that Johnny loved, and his niece played this song to him, on her iPhone in the hope it would comfort him.

Throughout the following day Johnny's breathing became more laboured, but he was comfortable as his secretions were better controlled. Many times, when interviewed, staff expressed relief that this had been achieved.

> S2: *"He was extremely comfortable and thank god we got to that […] Yeah that he didn't die as people would say roaring, he didn't*". [814]

Johnny passed away in the presence of his family, who stated in qualitative comments in the QODD, that they had felt

> *"very helpless and maybe inadequate and dependent on the very kind staff members".*

5.3.3. Case study 3: Finbarr

Finbarr had a severe ID and lived in residential care all his adult life. As he aged, he had several co-morbid health conditions and his health deteriorated until he died at the age of sixty-one. His sister Maria, along with several other professionals was integral to his *"Circle of Support"* (see Figure 9).

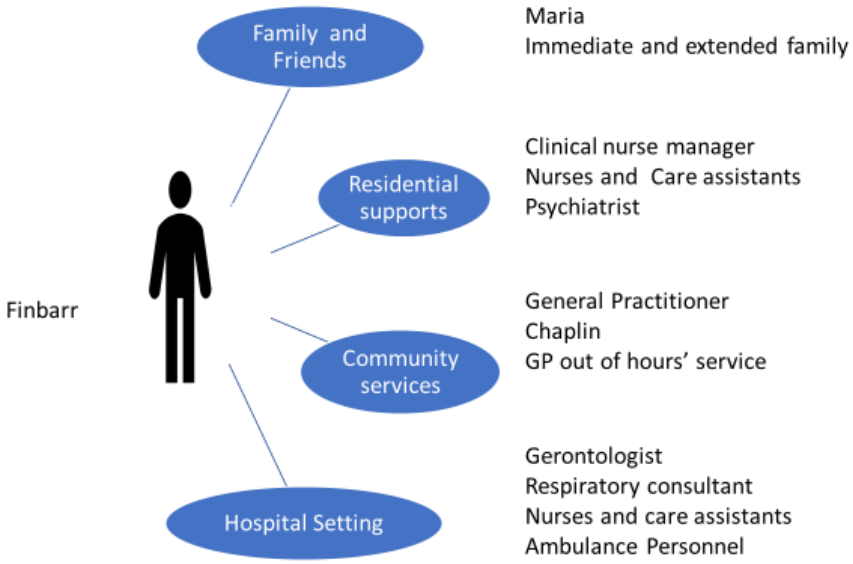


Figure 9: Finbarr's Circle of Support

Finbarr communicated non-verbally and staff in the community group home who supported him understood his non-verbal forms of communication.

> S3: "*We knew how far to go with him as well, with discussion, if we knew he wasn't going to understand something we wouldn't say it to him".* [76-78]

His family too, reiterated the importance of having people with him who could understand him and be familiar with his needs as Finbarr could be quite distressed and anxious in unfamiliar settings.

5.3.3.1 Change in health status

Five years before Finbarr died, he was diagnosed with dementia. ID staff indicated that around this time they noticed some changes in Finbarr. He began to hoard things, could get confused about schedules and began to slow down a little. Despite this, ID staff considered him to be healthy and, when interviewed, indicated that the gerontologist often commented on how healthy he remained, despite his co-morbid health conditions. His family too indicated that his health was not a cause of concern leading up to his death;

F3: *"Really up to two weeks before he died, he was happy, and he was you know able to do things".* [50-51]

5.3.3.2 Change in focus of care

During October, three months before Finbarr died, staff referred him to the GP as they felt he was lethargic and a little bit chesty. The GP indicated in the medical notes that he had a head cold and prescribed an antibiotic, paracetamol and vitamin C. For the next seven days, Finbarr remained lethargic and seemed to be chestier. He was reviewed by the GP who documented in the medical notes that Finbarr continued to be lethargic, but his chest was clear, and a urine sample was obtained to test for signs of infection. Blood tests were taken, and two days later he was reviewed by the GP again, who queried a viral infection and commenced another antibiotic.

In the following days, Finbarr began to recover. According to the nursing notes he appeared to be stiff when walking and his level of mobility was deteriorating. Staff indicated that there was no evidence of injury, he wasn't complaining of pain, he just seemed to be slowing down. The natural rhythm of his life continued during the end of October and into November when he attended outpatients' appointments, one for the removal of a benign skin lesion and the other for urology investigations. On two occasions, Finbarr was reviewed by the GP, as he was hypotensive. The GP queried why this might be and indicated that he would organise further medical tests to be done.

At the start of December, Finbarr was in good form and went out for the day with his sister. However, staff indicated in the nursing notes that he then became off-form and confused, and staff were closely observing him. Six days before Finbarr died, he stayed in bed until lunchtime, and nothing unusual was noted about him until 1.45 am when he became restless. At 2.05 am he became distressed and his breathing was shallow and weak. The GP out of hours' service was contacted but were unavailable so an ambulance was called.

He was commenced on O_2 by the paramedics according to the nursing notes and appeared to be much improved when transferred to hospital. On admission, an ECG and a chest x-ray were done. Finbarr commenced on IV antibiotic's and O_2 therapy for five days. He was described as tired but comfortable and responsive in the nursing notes. Staff in the residential home contacted his family and informed Maria of the situation. At this point, the residential home was not able to send a staff member to stay with Finbarr all the time, but throughout the following days, whenever feasible, ID staff did stay to support him and the family.

5.3.3.3 Transitioning to end-of-life care

Four days before he died, Finbarr began to deteriorate, and Maria requested that no further investigations or tests be carried out. In her interview, Maria indicated that Finbarr did not like to be in hospital, even for outpatients' appointments and would have to be given an anxiolytic[5] prior to these. She remarked that she had seen Finbarr looking around at the machines in the hospital and knew he was afraid. Additionally, Maria reported that Finbarr would get distressed when in pain and because of his communication difficulties Maria was afraid that he would not always be able to indicate if he was in pain.

> F3: "W*hether there were other interventions that could have been made for him at that time, my understanding was they would have been very severe and would have caused him a lot of pain and you know everything that could be done was done without him having to you know suffer too much".* [26-30]

Finbarr was unaware of the decisions being made about him and Maria indicated that she did not feel that he would have the capacity to understand the situation even if she had discussed it with him. From her responses in the QODD questionnaire, Maria indicated that she did not really know whether she had truly respected his wishes regarding his end-of-life care as she could not say for definite what his wishes were. The ID staff indicated that they were of the same view on the basis of their responses in the SPELE.

5.3.3.4 The final days

Maria stated that it was not really until his last three days in hospital that both she and her siblings began to realise that Finbarr was not going to recover. As Maria simply put it,

> F3: "*I suppose we didn't realise he was dying".* [91-92]

At this point, Finbarr's condition deteriorated, he went into respiratory arrest twice, was resuscitated and stabilised, and all his family were contacted. A DNR was put in place, following consultation with the family. Maria could clearly remember this discussion and indicated when interviewed that, at this point, his future quality of life was a significant factor.

> F3: "*I think we saw how desperately uncomfortable he was from having to have the mask and the drips and you know not understanding why and we felt that you know that while things might be prolonged for a while quality wise for him that it wouldn't have been good".* [72-75]

[5] Anxiolytics are prescription drugs used to treat and prevent anxiety disorders. Anxiety is an emotional state in which fear dominates a person's life https://www.encyclopedia.com/science/encyclopedias-almanacs-transcripts-and-maps/anxiolytics

At this point, ID staff made significant efforts to go and support the family and to spend time with Finbarr themselves. The ID staff liaised with the family and tried to be in the hospital to give them breaks and were always there when the family could not be. The family acknowledged this support;

> F3: "*it was so great that the girls from [name of residential home] were up so much, if we weren't there myself or [sibling] one of them was there, I don't think he was ever [alone] except maybe at night when he was asleep that he was without somebody who kind of knew him very very well".* [88-91]

Maria indicated that the staff in the hospital were fully supportive of the family; they moved Finbarr to a private room and visiting hours did not apply to the family or ID staff. The family were made aware of accommodation available to family members by the hospital staff and they availed of this as none of them lived locally. The Chaplain attached to the community home administered the last rites and stayed with Finbarr and the family in the hospital as much as he could. Two days before he died, ID staff, discussed the funeral arrangements with Maria as documented in the end-of-life form in Finbarr's file. According to the nursing notes, Maria wanted the staff to make the arrangements for his funeral and the staff did this. That evening Finbarr awoke, smiled and appeared brighter, but then lapsed back into unconsciousness.

The day before he died, it was documented in the nursing notes, that Finbarr's condition had worsened, his colour was poor, and he was unsettled during the night. He was agitated at times and would take the O_2 mask off, and his breathing would become laboured. The morning that Finbarr died, an off-duty ID staff member from the residential home went to the hospital and stayed with Finbarr and his family in her own personal time.

Finbarr passed away peacefully in the presence of his family that evening. Based on their feedback in the QODD questionnaire, his family, while aware that, Finbarr was fearful about being in hospital, felt that his end-of-life care was good. The family never queried if it would be possible for him to return to the community home before he died. Staff too felt the quality of care provided to Finbarr was good but stated that it was difficult when individuals end up dying in hospital, as those who heretofore have cared for them, can no longer do so. The view of one staff member, cited below, was that when people were in same residential home for most of their lives it would be preferable for them to die there.

> S3: "*It's really letting go of them from here is the thing, that they are out of our care really I suppose. And I think it would be a privilege to have people die here I suppose as a lot of them have spent most of their lives here, so it would be lovely for them to have died here".* [40-43]

5.3.4 Case study 4: Charles

Charles had a severe ID and lived in residential care for most of his life. Charles had a number of co-morbid health conditions and died at the age of fifty-one. His sister Nora, along with several other professionals were integral to his *"Circle of Support"* (see Figure 10).

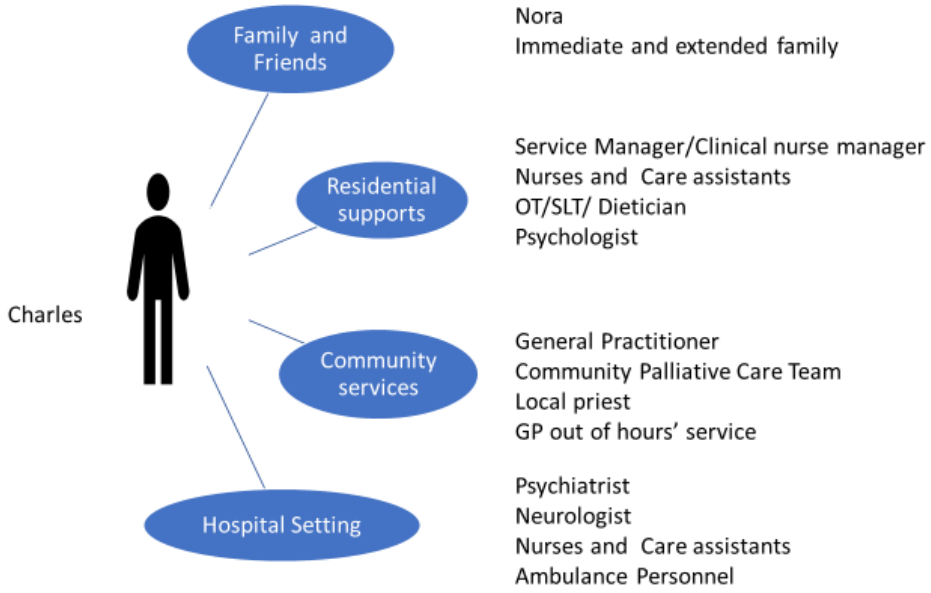


Figure 10: Charles' Circle of Support

Charles was diagnosed with dementia with some parkinsonian and frontal lobe features three years before he died, prompting his transition from one community home to another. His family were consulted and recognised the changes in Charles. Following this, Charles was quite stable overall, according to his nursing notes. Staff were advised to keep him under constant review and to facilitate community engagement and family contact.

5.3.4.1 Change in health status

Two years before Charles died his health declined further. He lost his mobility, was in a wheelchair, and had difficulties accessing day services. Fourteen months before he died, he was hospitalised and successfully treated for a co-morbid health condition. He was diagnosed with late onset myoclonic epilepsy in Down Syndrome (LOMEDS).

His epilepsy profile stated that he had recently begun to have tonic-clonic seizures, with a noticeable increase in jerking and twitching of limbs and was treated with an anti-convulsant[6]. He could become agitated and vocalise prior to seizures and was treated with benzodiazepine for this.

5.3.4.2 Change in focus of care

Ten months before he died, Charles' family indicated in a letter to the community home that he was not for resuscitation following a discussion with the GP. This letter stated the following:

> *"In the event of a life-threatening event and due to the terminal nature of his condition Charles is not for resuscitation".* [extract from letter]

Charles was not involved in this discussion and was unaware of the seriousness of his health issues. Nora stated, when interviewed, that she did not feel he would have been able to comprehend the situation and indicated in the QODD questionnaire that while the GP discussed his end-of-life care with the family, the GP did not talk to Charles. Data from the SPELE questionnaire, completed by staff, indicated that the GP also spoke to staff who knew Charles well in in relation to his end-of-life care. The nurse supporting him indicated that, generally, people like Charles were not told they were dying for two reasons. Firstly, the nurse felt that many of the individuals supported in the service had experienced enough trauma in their lives and didn't feel they should be burdened with this information. Secondly, by the time people came into the service, individuals had deteriorated quickly, or their capacity was already significantly impacted, and they could not make a decision.

> S4: *"I suppose they have had enough traumas in their life, I don't feel they need to be burdened with that. I suppose it would be different if somebody got an illness where we you know, where we knew they were dying and were still aware and able to make a decision. Where I suppose our experience to date have been people have deteriorated either very quickly or their capacity has been quite diminished".* [559-564]

In the eight months prior to his death, Charles had periods of becoming chesty and was treated with antibiotics and Combivent via a nebulizer. A pattern of being alert and energetic and then becoming lethargic during the day commenced. Six months before his death, staff became concerned over increasing episodes of jerkiness and Charles began to lose his appetite and have issues with skin integrity.

[6] An anticonvulsant is any one of a class of drugs used to prevent or alleviate convulsions. https://www.collinsdictionary.com/dictionary/english/anticonvulsant

Charles then started to become extremely jerky and was distressed by this and staff called the GP who indicated in the medical notes that, as per the advice of his neurologist, the dosage of benzodiazepine [7]could not be increased. However, the GP indicated that the medication could be given more often if required as he was charted for the medication PRN[8]. Over this time, staff and his family continued to maintain the natural rhythm of his life and he went on social outings with family and attended day services at times when he could. Overall, staff described his rate of decline as gradual, as indicated in their responses in the SPELE questionnaire.

The month before he died, Charles had significant respiratory issues and began to be treated for congestive cardiac failure. The GP prescribed several medications to manage his symptoms and he was to commence on O2 if his Sp02 levels dropped below 90%. At the end of October, Charles had a tonic-clonic seizure which was severe and lasted for 30 seconds. He was slow to recover but was alert that evening. The following day he attended his day service for part of the morning, however, he was tired in the evening and became chesty. He did not attend the day service again after this.

5.3.4.3 Transitioning to end-of-life care

At the start of November, it was reported in his nursing notes that Charles was chesty, distressed and agitated. He was reviewed by the GP and his medication regime was altered to address these symptoms. He had a severe myoclonic jerking episode at lunchtime and responded well to medications. He was relaxed that night but required 0_2 and he improved slightly. His family were informed of the situation and staff indicated that they felt at this point, Charles was not going to improve.

During this time, Charles continued on 0_2 and was largely unresponsive and, according to the nursing notes, the GP referred him to the local hospice for assessment. The GP prescribed medications to be administered subcutaneously if Charles could not take oral meds. According to the nursing and medical notes, he was visited by his family and the GP returned that evening and commenced him on Midazolam PRN for agitation and discomfort. He remained relaxed and slept most of the night, and his family discussed Charles's situation with the GP. However, this discussion was not documented.

[7] A group of medications used to treat anxiety, agitation and restlessness, epilepsy, mania, alcohol with drawl and sleeping problems. https://www.rcpsych.ac.uk/mental-health/treatments-and-wellbeing/benzodiazepines

[8] PRN- as needed or as required

The nurse supporting Charles encouraged Nora to talk to the family about Charles.

> S4: *"So that was where I kind of had a lot of work with Nora in saying look now take all the information, go home try and call a family meeting and talk about the possibility of what will happen Charles in the not so distant future and that you know but just explain and then obviously have linked with Dr [doctors name] so you get more information and then come back to us and to Dr [doctors name] with a family decision".* [274-297]

His family discussed the end-of-life form, which documented religious and funeral arrangements and was completed by his mother three years previously. Charles' sister Nora indicated the positive impact of having this form completed in advance.

> *F4 "In my experience having had the end-of-life/ funeral plans already in place with some time made dealing with Charles's death easier".* [written feedback from QODD]

5.3.4.4 The final days

A week before he died, Charles was reviewed by the GP, the CPCT and was catharised. No urinary output was recorded from the catheter and the GP out of hours' service was contacted. The doctor removed the catheter at 5 pm and was concerned that trauma to the ureter had occurred while the catheter was put in situ due to the presence of blood. The doctor did not re-catharise on that basis. The bleeding stopped but he did not pass urine until late that evening.

Over the following days, Charles experienced a deteriorating respiratory condition, ongoing jerkiness, agitation and distress. These symptoms were successfully managed by the ID staff involved in conjunction with the GP and the CPCT using a combination of medications and O_2. When interviewed, the nurse involved informed me that he had a long conversation with Nora as he felt that Charles could die at any point. That this conversation took place was documented in the nursing notes, but specific details were not documented.

> *S4: "Four or five days beforehand we could see he is not coming out of this. It was very much then we said right you know; you need to make a decision of whether you want to be here or not for it. And we really had to explain as well then what would happen when he was actually dying".* [287-291]

Nora indicated that being informed of this was beneficial to the family;

> *F4:" Being given warning that the end was near, rather than sudden allowed us precious time with him which also helped with the subsequent grieving process".* [written feedback from QODD]

Over the following days, Charles was in a semi-comatose state. He was reviewed by the GP and his oral medications were discontinued apart from his anti-convulsant which was administered if he could tolerate it. At this point, the impact of staying with Charles over several days was taking its toll on the family;

> *F4: "We were trying to decide then what do we do because I think exhaustion was probably hitting in as well with some of us then at that point as well because most of us had been up during the night as well with him".* [368-370]

According to data from the SPELE questionnaire Charles was comfortable in his final days. He presented with several symptoms such as pain, shortness of breath, agitation and restlessness and a decreased appetite and fatigue, but these symptoms were well managed. He had seizure activity, constipation and dry mouth which were well managed. He appeared comfortable and at ease most of the time; he did not appear frightened or sad. The ID staff continued to liaise with the CPCT when required.

Team meetings were held daily to discuss his care and staff indicated that a care plan was in place where his wishes, spiritual needs and religious and cultural beliefs were met. Supporting the family over a protracted period of time was intense, however staff were happy to do it.

> S4*: "At some stage you are thinking you are actually spending more time counselling and supporting the family than you are the individual. Charles was almost the easier part of it, do you know. Because Charles was doing his own thing and I suppose we were just continuing and obviously the intensity of the care for Charles just became more".* [49-58]

It was documented in the nursing notes, that Charles had a tonic-clonic seizure two days before he died which lasted one minute. The CPCT arrived and commenced him on a syringe driver. He appeared weaker and less responsive after the seizure; his breathing became laboured that night. The CPCT was contacted and advised on medication. The day before he died, Charles was comfortable in the morning but began coughing and was cyanosed and became distressed. The CPCT did not feel that Charles was benefiting from O_2 therapy and following discussion with the GP, it was discontinued. The CPCT changed the dosage of his medications in his syringe driver. Overall, he spent a comfortable night, but his abdomen appeared swollen.

According to the nursing notes, the day Charles died he appeared more settled. The CPCT contacted the unit and were informed that his abdomen was distended and advised staff to contact the GP out of hours' service, who catheterised Charles. Over 250mls of concentrated urine was immediately drained and later that afternoon, a further 250mls of urine was drained from his catheter.

At 3pm a new syringe driver was put in place by the CPCT and Charles passed away in the presence of his family at 3.37 pm. Staff were emotional at his passing and spoke of the intensity of the relationship with him and the family;

> *S4: "We had such a close relationship, we were emotionally invested as well in the client because you've known them for years and then the family as well, I suppose, like with them we were very lucky because we had a very close relationship with all of them".* [27-29]

His family were deeply appreciative of the standard of care provided to Charles and to them.

> *F4: "The staff that were on duty made lunch for us and we weren't expecting anything like that. But when we were sitting down eating, the two girls on duty went down to his room and were holding his hands and that for me was just the ultimate of care".* [387-390]

Staff indicated that after his death, the family were provided with an opportunity to discuss his care and were satisfied with the service. When completing the QODD questionnaire, the family rated Charles' end-of-life care as "*almost perfect"*.

5.3.5 Case study 5: Frank

Frank was a man with a mild ID who lived in residential care all of his life. As he aged, his health began to deteriorate, necessitating a move from one community home to another community group home two years before he died, at the age of eight-six. His sister-in-law Emma along with several other professionals was integral to his *"Circle of Support"* (see Figure 11).

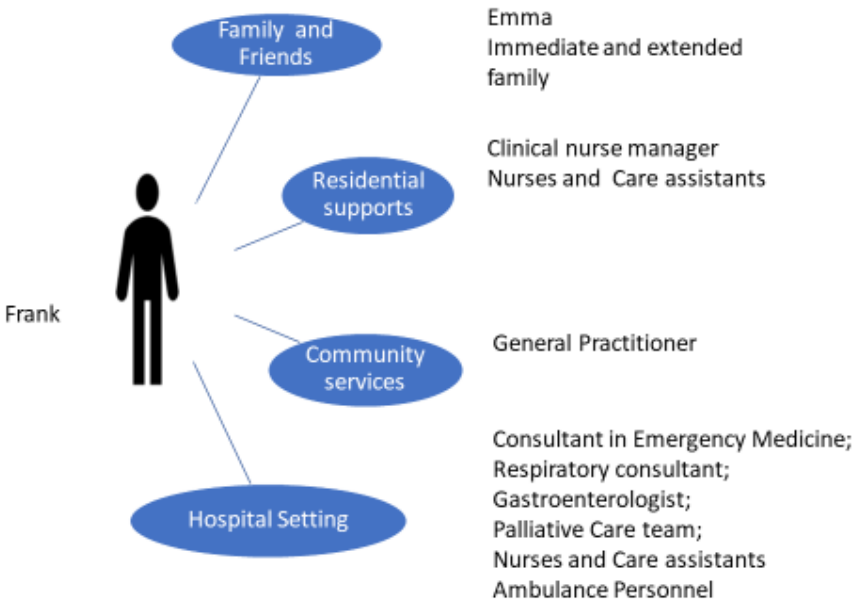


Figure 11: Frank's Circle of support

On admission to the community home, Frank had good communication skills and staff were able to explain things to him and support him to make decisions. It was clear from documentation in his file, that Frank was able to make various decisions in relation to his medical treatment. For example, he signed his own consent forms for sharing of personal information and admittance to hospital for emergency treatment. Just over three months before he died, Frank wished to purchase an expensive item, to help maintain his independence. The ID staff availed of an independent advocacy service to explain all aspects of the transaction to him and he made the decision to go ahead with the purchase. Up to two months before he died, despite his co-morbid health conditions, the natural rhythm of Frank's life continued. He attended his day service when he wished, and he continued to engage in his social life.

5.3.5.1 Change in health status

Two months before Frank died, he woke one morning in October and *was "very quiet in himself"*. According to the nursing notes, he refused to go out for a day trip which was unlike him.

He did not appear to be ill, but was reviewed by the GP the following day, who noted that his abdomen was distended and tender, and commenced him on an antibiotic. Two days later he saw the GP again as staff felt that his energy levels were low. The GP decided to commence him on another antibiotic as a precautionary measure. His appetite continued to improve in the coming days and his energy levels appeared to improve.

In the middle of October, Frank was once again reviewed by the GP. The results of his blood tests were returned and a UTI was confirmed and he required another antibiotic. Apart from this, the GP noted in his medical notes that no other significant health issues had been identified from the tests. For the next six days, Frank was in good form, his appetite was good, and he went on several social outings.

5.3.5.2 Change in focus of care

During this time, staff noted in the nursing notes that Frank was withdrawn and that he was uncooperative with staff when attending to his hygiene needs. He was reviewed by the GP who reported in the medical notes that his abdomen was distended and advised that he attend the A&E department. Frank was sent to hospital, had an abdominal x-ray and was comfortable. He remained in A&E the following day, a scan of his abdomen was taken, and Frank commenced on IV fluids. He was transferred to a ward and the possibility of a sigmoidoscopy[9] was discussed.

ID staff expressed surprise that Frank had become so ill so quickly and that he needed to be admitted to hospital. The staff member, when interviewed stated that she had come off night duty and:

> S5 "*I got a phone call to say that Frank was unwell, and I said I couldn't believe it because when I left, he was fine".* [106-107]

The following day Frank began fasting for a sigmoidoscopy. ID staff had to come to the hospital to meet his personal hygiene needs as he did not want the nurses in the hospital to assist him. It was indicated that he might require a colonoscopy. [10]Frank was given Picolax[11] in preparation for the sigmoidoscopy which seemed to have a good effect on clearing his bowel, and medical staff queried if he had been obstructed. The sigmoidoscopy was postponed for several days at this point. Frank was comfortable and was said to be in good form for the next two days.

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[9] Flexible sigmoidoscopy is a procedure in which a trained medical professional uses a flexible, narrow tube with a light and tiny camera on one end, called a sigmoidoscope or scope, to look inside your rectum and lower colon, also called the sigmoid colon and descending colon

[10] Examination of the inside of the colon using a colonoscope, inserted into the rectum. A colonoscope is a thin, tube-like instrument with a light and a lens for viewing. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/colonoscopy

[11] Picolax is used to empty and cleanse the bowel before examinations, https://www.ouh.nhs.uk/patient-guide/leaflets/files/100211picolax.pdf [Accessed on the 6/9/2018]

Eight days after Frank was admitted, it was decided to conduct an x-ray of his bowel and abdomen and the registrar indicated to the ID staff who were supporting him in the hospital when he needed procedures done, that a decision on further tests and treatments would be made when the results of the x-ray returned. A chest x-ray was scheduled for the following day and he was prescribed Combivent. Frank was scheduled for a colonoscopy, but this was cancelled as he was too unwell at this time. He was complaining of chestiness and was coughing, he had tachycardia and was hypertensive. Frank became breathless during the night and was treated with O_2 therapy. It was documented in the community home nursing notes the following day, that medical staff from the hospital staff were in contact with the home to discuss issues relating to consent to medical treatment. However, what was discussed, and with whom, was not documented. Frank had a chest drain inserted that evening due to his chest infection. He remained stable for the following two days and then on the 2nd of November, thirteen days after being hospitalised, he was diagnosed with MRSA. He refused to co-operate with medical staff, when having blood taken. When ID staff attended the hospital, he allowed the medical staff to take blood, according to the nursing notes. Frank appeared to be recovering slightly and was in much better form and a sigmoidoscopy was carried out and he was diagnosed with colonic volvulus[12].

Frank's condition remained unchanged for the next two days, he had a chest drain in place and was on IV fluids. His family confirmed that a decision was made by his consultant to undertake surgery on his bowel and the family consented to this procedure. Initially, Frank recovered well postoperatively, but then began to deteriorate. His sister-in-law Emma stated that he was in a lot of pain following this procedure:

> S5: "*Frank was eighty-six years of age and the procedure really I suppose wasn't as successful as they thought it would have been and he deteriorated rapidly from there on and it really only took about, I suppose he was there for two weeks altogether, but the last five days were a bit horrific really if you like for him."* [21-25]

5.2.5.3 Transitioning to end-of-life care

The hospital contacted the community home four days before he died and requested staff from the ID service stay with Frank on a full time basis, and this request was complied with. He was unwell that night but was comfortable. The following day Frank was distressed, and Emma was unhappy with his care at this point, she felt that he was in pain.

[12] Colonic volvulus is a common cause of large bowel obstruction worldwide. It can affect all parts of the colon, but most commonly occurs in the sigmoid and cecal areas.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3577612/

She acknowledged that the staff in the hospital were prescribing analgesics both orally and intra-muscularly but did not feel these medications were strong enough.

> *S5 "I was very upset myself really because they hadn't done anything about it, they knew he wasn't going to get any better, but they hadn't done anything about a lot of pain relief for him at that stage and I suppose if you like I was a bit mouthy [about the level of pain he was experiencing]".* [44-49]

At this point the palliative care team within the hospital became involved and Frank was commenced on a syringe driver. His family were relieved at this and happy with the quality of care provided at this stage.

> S5: "*I couldn't say a bad word about them in the [hospital], the palliative staff were there and they were in and out to him and they changed the bed three or four times a day to make him as comfortable as possible and as I said all the staff they took it in turns to come in from [residential home]".* [66-70]

5.5.3.4 The final days

Frank continued to deteriorate, and his medications were adjusted to better manage his symptoms of pain and chestiness. His family and ID staff remained with him and he remained unconscious for the day. The ID staff indicated when interviewed that they did not believe that Frank knew how ill he was. In qualitative comments documented in the SPELE, ID staff stated that they believed Frank assumed that he would return to the residential home following treatment. The staff talked about how important his bedroom was to him and that it was filled with treasured possessions and personal items. Once it was clear to the ID staff that he was not responding to treatment and they would not be able to transfer him home, they tried to bring the atmosphere of home to him:

> S5: *"Staff stayed and sang to him as he loved music and spoke to him about funny past stories etc."* [qualitative comments from SPELE]

Frank passed away in the presence of his family and ID staff. Both parties felt that he was at peace and comfortable at the end of his life. Emma stated that she felt that she not only had a duty to care for Frank at the end of his life, she also had a duty to her deceased husband:

> F 5: "*I was sad myself, but I just felt that was my duty if you like to my husband because my husband loved him, absolutely adored him".* [108-109]

5.3.6 Case Study 6: Louise

Louise had a moderate ID and lived at home with her family until her health began to deteriorate. Five years before her death she was admitted to a retirement home, having been hospitalised for a respiratory condition, where she died at the age of sixty-three. Her sister Siobhan, along with several other professionals, was integral to her *"Circle of Support"* (see Figure 12).

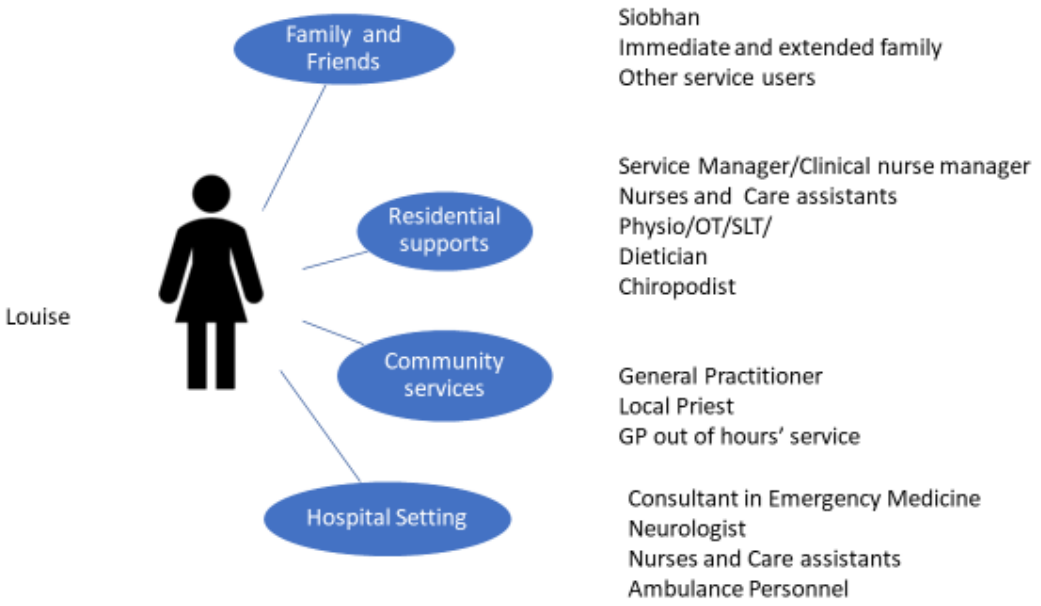

Figure 12: Louise's Circle of Support

On admission to the retirement home, Louise required full assistance with activities of daily living. She had respiratory issues and myoclonic jerking and was diagnosed with LOMEDS and attended a neurologist. Louise was doubly incontinent, her posture deteriorated, she was slow to swallow food, and was under the care of an SLT and dietician. Louise had good receptive but limited expressive communication.

The GP prescribed prophylactic antibiotics for Louise given her recurrent respiratory conditions. When she was dehydrated, she was commenced on subcutaneous fluids. Siobhan signed a form consenting to Louise being admitted to hospital if required. This form was a standard form developed by the organisation involved as part of their admissions process.

5.3.6.1 Change in health status

Two years before she died, Louise was hospitalised and remained in type 1 respiratory failure despite treatment. Siobhan and the consultant decided that Louise was for no further investigations and she subsequently improved and was discharged. Siobhan recounted her discussion with Louise's consultant:

> *S6: "But at some stage he had to come and say, 'what quality of life has the patient. What are we doing to the patient, she doesn't have the capacity to say yes, or no if you are sticking this in her, sticking that in her"?* [31-37]

Having made this decision with the consultant, Siobhan sent a letter, to the retirement home stating that Louise was not for further aggressive treatment, and that:

> *"A DNR is to be maintained on Louise "*[extract from letter]

Siobhan made this decision based on the co-morbid health conditions Louise presented with and because Louise could no longer indicate if she was in pain. Siobhan stated that Louise had been upset and distressed while in hospital. Watching Louise struggling for breath impacted on Siobhan and her perception of the impact of dementia on Louise.

> *F6 "I think in one sense that was a grace that she had the dementia, that she couldn't, and I think that is how she lasted so long because she was literally at stages where she couldn't breathe. It must be terrifying and if you remember that and you think this is going to happen to you again, you are going to get a panic attack but because she was in the permanent now due to the dementia, she didn't remember the traumas that she had gone through every time she got so sick".* [288-292]

Siobhan requested that Louise was for comfort care including pain relief. Siobhan stated that Louise was not capable of making decisions at this point and the service manager indicated, while being interviewed, that she explored several avenues to get a sense of what Louise would have wanted.

> *S6: "I didn't take it that there was any great decisions made by Louise, I was really going from what I had read in her medical file, when I had conversations with staff who had been very familiar with Louise and Siobhan and then when I met Siobhan it was really Siobhan who gave me most of the insight into kind of her wishes".* [235-237]

Generally, when unwell, Louise was reviewed by the GP and commenced on antibiotics and subcutaneous fluids.

These interventions were documented in her nursing and medical notes. However, following periods when she was poorly, Louise would recover and enjoy periods of being quite well overall.

5.3.6.2 Change in focus of care

In the last year of her life, Siobhan felt that Louise was deteriorating;

> *F2: "There were times you would go into her and she would be looking around, she would be comfortable, she was beginning to tire out I'd say in the last year, she would be more asleep than awake.'' [280-283].*

In January, ten months before Louise died, it was reported in her nursing notes, that she began moaning from time to time and facial grimacing was observed. She was prescribed paracetamol PRN for generalised pain as staff could not confidentially identify the cause of her pain.

Louise had a neurological review and no changes to her management were required. She was nursed in bed when unwell, but engaged with activities and social outings when well, as staff sought to maintain the natural rhythm of her life. This continued until March when the GP determined she was no longer able for such activities. Staff indicated in responses in the SPELE questionnaire, that Louise was in a state of slow decline.

In March**,** Louise appeared to be moaning a lot while sleeping at night. A pain assessment was completed, and her medication was reviewed but again no specific cause for her pain could be identified and she responded well to PRN pain relief. She continued to present with myoclonic jerking, and an audible wheeze in what was, by now, a usual pattern for her. Louise had a chest infection in April and by the start of May she had recovered, until later in the month when she suddenly became ill again.

Louise developed a significant chest infection and was coughing constantly. She commenced on an antibiotic and subcutaneous fluids during the day and that night, staff called the GP out of hours' service. It was recorded in her nursing notes that the service was unable to send a doctor and recommended calling an ambulance. Her sister Siobhan was contacted, due to her stated wish that Louise no longer be transferred to hospital.

When interviewed, Siobhan indicated that she left the decision whether to transfer Louise or not to the nurse on duty. Louise was sent to the A&E department by ambulance and was treated for a respiratory infection and pneumonia until the second week of July when she returned to the retirement home.

Reflecting on this, Siobhan indicated that she felt that sometimes people are transferred to acute hospitals because there is only one nurse on night duty in these services. If a person becomes acutely ill, they have to be transferred as there are not enough staff on duty to manage their needs as well as the needs of others in the service.

> *F2 "I always feel she was given excellent care in [residential home]. But I also have to understand and acknowledge you have a nurse on their own there at night and if something happens, they want them out and they want them in hospital whether they actually need to be there or not".* [488-503]

Louise had a chesty cough on return to the retirement home and was moaning from time to time. The CPCT became involved with her two months before she died. Recommendations were made in relation to pain medications which were recorded in her nursing and medical notes and Louise appeared to improve in the following days. The CPCT reviewed her a month before her death and considered her to be more stable and indicated they might discharge her from the CPCT service on their next visit.

5.3.6.3 Transitioning to end-of-life care

During September, Louise had an intermittent cough and staff reported in the nursing notes that she *"teared up"* while being fed. She had a prominent wheeze at this time and medication was administered via a nebulizer. Her blood pressure dropped, and she was repositioned to counteract this. The GP out of hours' service was contacted at 6.30 pm and indicated that Louise should be transferred to hospital. Siobhan was contacted and reiterated that she did not want Louise to be transferred.

> *F2: "But then I would be a strong enough person to have said, you know, it was like when the nurse rang that [day] and I said, 'no', and [name of doctor] came on and I said, 'read the file'. It says, 'not to bring her back', and I said, 'I don't want her going back', and I said, 'she is under palliative care, ring palliative care'. That is where she ended up staying, do you know. Because I wouldn't put her through all those bloody tests again".* [534-551]

Louise was charted for an antibiotic and it was suggested that her palliative care regime be reviewed, and this was documented in her nursing and medical notes. O_2 was administered as required and an audible crackle and wheeze continued to be evident throughout the night. She was seen by the local GP the following day and, Siobhan indicated the GP supported her decision that Louise stay within the retirement home. Staff indicated that a specific care plan was developed for Louise around this time and the GP, CPCT and the family were involved.

Staff emphasized the importance of supporting the family at this stage:

> *S6: "When a person is dying in this setting, the family are very much supported and in turn the person who is dying is also supported".* [qualitative quote from SPELE questionnaire]

5.3.6.4 The final days

At the start of October, Louise had shortness of breath, a cough, constipation, dry mouth, secretions, fatigue and a decreased appetite, as documented in the SPELE questionnaire. It was indicated that these symptoms were well managed.

Louise developed an audible wheeze and was moaning, especially during the night, but she responded to PRN pain relief. This pattern continued for the coming days, but she could also eat and sit out with support. Seven days before she died Louise's breathing was laboured, her SpO_2 readings were 89%, but for the next three days her respirations improved, and it was reported in the nursing notes that she was comfortable. Four days before she died, she became chesty again and appeared in distress. The CPCT attended and commenced Louise on a syringe driver.

At this time, Louise was accommodated in a single room. Staff and her family felt that she was comfortable most of the time and did not recall her crying or appearing sad or frightened. Her family had the same perspective in relation to her emotional state, according to the data from the QODD questionnaire. In her final few days, staff indicated that Louise was drifting in and out of consciousness.

For the following two days Louise was described as comfortable and she was closely monitored by the residential home staff and Siobhan and supported by the CPCT. On the day she died, it was reported in the nursing notes that Louise was comfortable throughout the day. Louise passed away that night in the presence of her family. Her sister rated the quality of care provided to her as *"extremely good"* and was happy with the support provided to both of them.

5.3.7 Case Study 7: Joanne

Joanne was an independent woman with a moderate ID who lived with her family until eight years before she died. She enjoyed a good social life and accessed an ID day support service. She had several health issues, which were well managed. Joanne was involved in the decision to move into the community home where she remained, until a year and a half before her death at the age of fifty. Her sister Lucy, along with several other professionals was integral to her *"Circle of Support"* (see Figure 13).

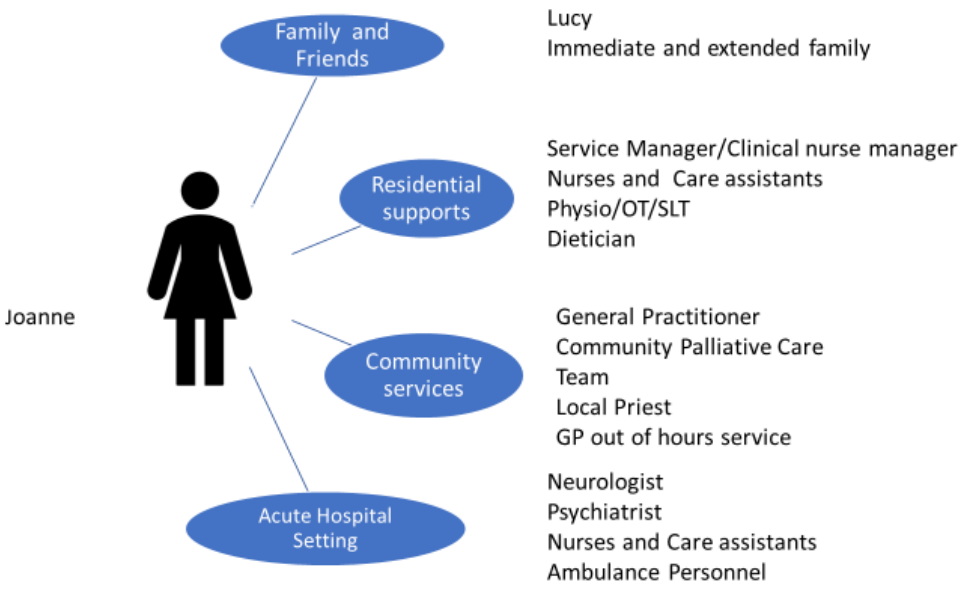

Figure 13: Joanne's Circle of Support

5.3.7.1. Change in health status

A year before Joanne died, ID staff expressed concerns regarding her cognitive ability, and referred her to a psychiatrist who queried the onset of dementia. Tests were done to rule out other co-morbid health conditions. Over the following six months, these tests, according to the psychiatrist's notes, indicated that Joanne had three undiagnosed conditions, all of which were subsequently appropriately treated. She was also diagnosed with Alzheimer's dementia and epilepsy. Eight months before she died, Joanne had a significant seizure and was hospitalised. On discharge, she was transferred to another small community home within the same organisation, due to her increased health needs. At this point, it was reported in her nursing notes that Joanne had excellent communication skills and could hold a full conversation with staff.

She settled well in the community home, and was quite stable for the following two months, though seizure activity and confusion remained an ongoing issue. Lucy was unsure how Joanne felt about her declining health stating that;

> *F7: "You know to be honest with you I think for her I really don't know how she felt or was she aware but for Joanne not be able to toddle around and walk for me it was very hard to see that".* [291-294]

Six months before Joanne died, she was hospitalised for a period of six days and was diagnosed with a Cerebral Vascular Accident (CVA) and seizure activity. It was documented in the nursing notes in the community home that Lucy asked that, if Joanne required palliative care, she be returned to the community home. The organisation agreed, once it was established that the service could provide for all her needs. Joanne did return to the community home and extra staff were assigned to ensure her needs were met. According to correspondence from the hospital, her condition was discussed with her family, who agreed that considering her co-morbidities and background of Down Syndrome, if any rapid deterioration were to occur no future active measures would be appropriate. She commenced on an anti-convulsant for her seizure activity. Although it was evident that Joanne was declining, no overarching plan or advance care plan was put in place at this time.

> S7: *"There was no directive from [organization's name] you know what we should do it was basically left to us as nurses you know you make the call [decide how next to proceed] like you are there you make the call".* [89-91]

A risk assessment was undertaken on her return from hospital which indicated that Joanne had an increased risk of falls and measures were put in place by the OT and physiotherapist to support her. Staff stated in her care plan that, when she was lucid, Joanne could indicate that she was in pain and, when she was not lucid, she was to be observed for facial grimacing and the Abbey Pain Scale was to be used. During the month of February, six months before Joanne died, it was recorded in the nursing notes, that she continued with a pattern of confusion, myoclonic jerking, issues with nutritional intake and problems with mobilising along with her co-morbid health conditions. In addition, Joanne had three significant seizures, the longest of which lasted for 14 minutes after the administration of buccal midazolam. She was made as comfortable as possible and was reviewed by the GP and commenced on O_2. Her anti-convulsant medication was increased as per her discharge plan. The family were contacted and were told they could visit whenever they wanted to, which they continued to do for the following five months.

At the start of March, it was stated in the nursing notes that staff discussed the use of midazolam, and the impact of it on Joanne after a seizure, with the GP. Staff felt that Joanne was extremely drowsy and lethargic following administration of the medication and that this impacted her quality of life. The GP advised that either the GP or an ambulance be contacted if a second dose of midazolam had to be administered to Joanne so that either the GP or the ambulance would already be en route should she have a poor reaction. The remainder of the month was mainly uneventful, and at the end of the month, she was reviewed by her neurologist who stated that she was recovering but would need more time to recover fully from the CVA. The neurologist indicated that her anti-convulsant treatment could be increased to gain better seizure control.

5.3.7.2 Change in focus of care

Three months before she died, during the month of April, the GP stated in the medical notes, that there was a general deterioration in Joanne. Despite an increase in her anti-convulsant medication she continued to have frequent episodes of myoclonic jerking. The GP stated that her family were aware of this deterioration but did not specify how the family had been informed. Four days after this, she was again reviewed by the GP who reiterated in the medical notes that Joanne was now deteriorating. She was reviewed by the SLT, who noted that while still capable of eating, Joanne required approximately 30 minutes to complete a meal and, since she was fatigued by this, she should be kept under review. An assessment of needs support plan was put in place by the service manager, which stated that the objective of the plan was to ensure that Joanne had a respectful and pain free end of life. The plan required that Joanne be kept pain free, be carefully monitored and reviewed by the GP as required, and that her family would be kept updated on her condition and that their wishes would be adhered to. The plan was updated two days after this, identifying who to contact in terms of GP support should Joanne deteriorate.

At this point a DNR Report was completed by the GP. The format of this report was specific to the organisation involved and recorded the reason for the DNR decision, who had been involved in the decision and whether the person subject to the DNR had been informed. This form stated that Joanne did not have capacity to make and communicate decisions about CPR (coronary pulmonary resuscitation) citing her recent history of CVA and general decline, as documented by the GP, and that, therefore, she was not informed of the decision. The GP documented that the GP, family and staff contributed to the decision, and the decision was signed off by the GP. During this month, Joanne had several seizures which were successfully managed in the community home and, overall, she was stable. However, it was noted by staff that there was an increase in her level of myoclonic jerking and her anti-convulsant medication was increased.

5.3.7.3 Transition to end-of-life care

The GP spoke to Lucy at the end of April, and again advised her that Joanne was in decline. Lucy requested that she be informed of all changes in her condition. Information gleaned from the QODD and SPELE questionnaires indicated that both staff and family members categorised Joanne's rate of decline as slow. Staff indicated that she had several specific symptoms including pain, shortness of breath, seizures, a dry mouth, agitation and restlessness which were successfully managed by the ID staff, in conjunction with the GP. According to the medical notes, the GP again contacted Lucy and, following a discussion, the GP reiterated that Joanne was not for active resuscitation and weekly bloods to monitor drug levels were to be discontinued as they were causing Joanne distress.

At the start of May, Joanne had a prolonged tonic-clonic seizure and was cyanosed. Buccal midazolam was administered as per her protocol without effect and she remained in respiratory distress and an ambulance was called. The GP, due to her DNR status and her previous history of CVA, did not feel admission to hospital was warranted. The ambulance crew who had arrived at this point, departed without Joanne who was commenced on O_2 and remained in a semi-comatose state. Her condition improved overnight, and she became alert and took fluids and oral medications the following day. Her future situation was discussed with the GP who advised that her epilepsy protocol should be followed and if she did not respond either the GP surgery or GP out of hours' service should be contacted as opposed to calling an ambulance.

Over the next ten days, Joanne was in excellent form, taking a good diet and was laughing and engaging with staff and her family. She then had a period of being quite jerky but did not have a seizure and was reviewed by the GP who advised staff to administer stesolid[13]. The CPCT visited and advised as to future medications. The SLT reviewed her and made recommendations regarding her food and fluid intake. Joanne settled for the following few days, took oral fluids, medications and stesolid was administered as required and she remained stable for the remainder of the month. However, her cognitive decline continued, and, at the end of September, Joanne attended the psychiatrist for a scheduled review.

Following this review, a letter to the service from her psychiatrist stated that Joanne did not have the capacity to assess her own medical treatment and that staff in the residential home, in line with their common-law obligations to act in her best interest, were to administer her medication regime.

[13] The active ingredient in Stesolid is Diazepam. Diazepam has anticonvulsant, sedative, and muscle relaxant properties. It is used in the treatment of severe anxiety and tension states, as a sedative and premedication, in the control of muscle spasm, and in the management of alcohol withdrawal symptoms. https://www.medicines.org.uk/emc/product/4475/smpc [accessed on the 6/9/2018]

Staff indicated that she lacked the capacity to make decisions regarding her care, place of death and type of death and, therefore, she could not contribute to these decisions. Meetings with the family, CPCT and GP were held at an informal level to discuss her ongoing needs. The staff involved acknowledged the importance of the relationship with the family at this point;

> S7: *"I suppose they are comfortable with us and we are comfortable with them there is a kind of a mutual respect I suppose between staff and families and families and staff kind of". [*623-625]

At the start of June, Joanne had a five-minute tonic clonic seizure and recovered well after stesolid was administered. It is documented in her nursing notes that the staff discussed the impact of buccal midazolam on Joanne with the GP. It was decided by the GP that stesolid was to be the first line treatment for seizures, with buccal midazolam being a second line treatment, as it appeared to make Joanne extremely drowsy and lethargic. Overall, she remained stable for the remainder of the month.

5.3.7.4 The final days

At the start of July, Joanne continued to decline and was drifting in and out of consciousness. At this point, staff reported in the SPELE questionnaire that Joanne was comfortable and at ease most of the time, and never appeared frightened or sad. Staff could not speculate if she was at ease with dying and could not rate her acceptance, insight, and control of her dying experience. Lucy however felt Joanne had some insight into her situation;

> *S7: "I was sitting beside her, and the tears were just coming down my face and out of everything she said, 'stop crying'. There had to be some awareness there in that she just said those two words and there was never a word really after that".* [493-497]

Eight days before she died, Joanne had a tonic- clonic seizure and stesolid was administered with effect. Over the following days, Joanne was observed having myoclonic jerking and staff had a discussion with the GP regarding her not for resuscitation and hospitalisation status.

It was agreed in the event of a non-cardiac incident, that everything that could be done to support Joanne in the residential home would be done. However, in this situation, the GP or GP out of hours' service would make the final medical decision on whether to transfer to hospital or not. The situation was discussed with the family. At this time Joanne had a further tonic-clonic seizure and was successfully treated as per her epilepsy protocol. The GP contacted the CPCT and Joanne commenced on a syringe driver for symptom control.

Over the following four days, Joanne had periods of chestiness and being jerky, but these symptoms were managed by the ID staff with the ongoing support of the CPCT and the GP. On the morning of the 4th day on the syringe driver Joanne passed away peacefully, surrounded by her family.

In her interview, Lucy spoke of the impact of her sister's death on her and indicated that she suffered significant psychological stress for over a year afterwards.

> *F7: "But it was all too much, and people said then the, 'Oh she was fifty she was a great age', but for me she wasn't. For me 'she was only fifty' you know I had a problem with that, or you know people with Down Syndrome they get Alzheimer's early, but she was my sister and she was fifty and for me it was young, that's all."* [361-365]

5.3.8 Case study 8: William

William had a moderate to severe ID and lived at home until four years before he died. In his earlier years, William was independent, with few health issues and had access to ID support services. As he aged, his health began to deteriorate, and he was admitted to the retirement home having been hospitalised with pneumonia. He remained in the service until he died at the age of fifty-six. His sister Elaine, along with several other professionals was integral to his *"Circle of Support"* (see Figure 14).

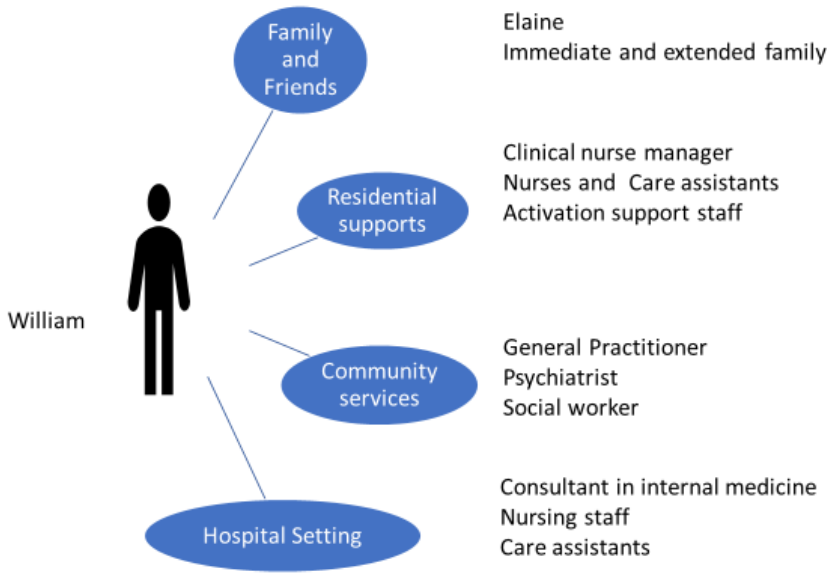

Figure 14: William's Circle of Support

William was admitted to the retirement home in April and, by September, was well settled, his speech and social interaction improved, and he was attending his ID day service five days a week. His family visited daily, he stayed with his siblings some weekends, and went on outings regularly. Shortly after being admitted to the retirement home, a place in another service became available. William's family believed this other service would be better suited to his needs and hoped he would move. The decision was left to him and he decided to stay where he was, to the surprise of his family;

> F 8: "*And it was a decision left to himself you know. And he said, 'I want to stay in [name of residential home]'. Sure we all kind of said, 'oh my god he doesn't want to go to the [other residential home]' and so my mother she went through the horrors [because he made that decision]".* [34-37]

Even though William's decision went against his family's wishes, it was respected. Elaine described the decision as a *"very informed decision"* as William had concrete reasons for remaining where he was.

5.3.8.1 Change in health status

Two years before William died, he began to display paranoid and uncooperative behaviour in his day service and staff were concerned that his mental state was deteriorating. He was reviewed by the psychiatrist in May and according to the medical notes, he commenced on antipsychotic medication. William was assessed for Alzheimer's dementia and this was ruled out. He was reviewed by a psychiatrist again at the end of May and his mental state appeared to improve and he continued on antipsychotics. He then began to recover and participate in activities. Moreover, William told the psychiatrist that he was having no psychotic episodes and he was maintained on his ant-psychotic medication at this time. At this point William was attending his day service and was in constant contact with his family. This was the natural rhythm of his life until he began to show less interest in attending the day service and reduced his attendance to three days a week.

William also suffered a significant bereavement, when an immediate family member died, which had a profound effect on him. According to the nursing notes, he was tired and withdrawn and had some bereavement counselling to help him cope with his grief. His antipsychotic medication was reduced at this point due to his lethargy and there was a notable reduction in his level of ability. In the following months, staff reported that he was doing better, and was once again involved in activities he previously enjoyed.

5.3.8.2 Change in focus of care

The year before he died, it was documented in the nursing notes, that William began to show less interest in attending his day service. William decided for himself, whether he wanted to attend or not, on a daily basis. In November, eight months before he died William was diagnosed with a previously undetected serious health issue.

His family were made aware that this diagnosis would significantly shorten William's life. The family made the decision not to inform William. Elaine stated when interviewed, that William was with her and her brother when they went to the consultant's office and were given the diagnosis. However, the family did not want to discuss his diagnosis in front of him, so they cut short the conversation and the consultant did not pursue it. The family made another appointment with the consultant to discuss the situation later when William was not there.

F 8: *"In front of William, we didn't want it, look it could have been done differently as well I could have taken away* William *and [name of other family member] could have spoken you know or maybe the doctor could have spoken to William I don't know".* [306-309]

Elaine acknowledged that they could have dealt with the situation differently and looking back after his death, she had regrets about not talking to him about his end-of-life care. Elaine openly acknowledged that William could make his own decisions and would have taken exception to his family making decisions for him. On previous occasions he had admonished Elaine for this.

F8: "S*ometimes I would be bossy, and I used to be a [name of profession] in one life you know and if I kind of got bossy he would take two steps back and he would point the finger and he would say, 'you are no [name of profession] to me you know'. So, you know, consultation, so he did like to be consulted in things".* [270-274]

ID staff also acknowledged that William was independent and made his own decisions. When he said "*no*" he meant *"no".*

In the final year of his life, William remained quite well for the month of January and the natural rhythm of his life continued. However, in February, he became more lethargic and decided to stop attending his ID day service. He did discuss this decision with the staff in the retirement home and his family, but the final decision was left up to him. At the end of February, William suffered another significant bereavement, when a friend died, and was upset. He developed a chest infection and was treated with antibiotics having been reviewed by the GP, who felt that he might need IV antibiotics if he did not improve quickly. His cough persisted, and he developed pneumonia and was hospitalised. He was in the intensive care unit (ICU) for five days and then began to recover having been treated with IV antibiotics. He remained in hospital for a further nine days and then returned to the retirement home.

On returning, he was still unwell, and the ID staff were informed that he would need O_2 therapy for periods of time going forward. The staff ensured that the equipment required was available to him on his return. William remained chesty overall, and again required an antibiotic and was given O_2 therapy when needed. He began to lose his appetite, was tired and vomiting on occasion. The GP indicated in the medical notes that the vomiting was associated with the health issue which had been diagnosed in November and that this illness was progressing. He prescribed antiemetic's, and William continued to take a light diet, but had little appetite for anything and was becoming more lethargic. He needed a wheelchair to move around but despite all this according to his nursing notes while his "*condition was poor he was still managing to smile".*

5.3.8.3 Transitioning to end-of-life care

Over the coming months, as noted in William's nursing notes, staff were led by him in terms of his daily care needs. He got up when he was able, was showered when he indicated he had the energy, but apart from this, he had bed baths. If he had the energy to go out with his family for a car drive, he went, but Elaine noted that he stopped asking to stay overnight with family members;

> F8: "From t*he March to May he didn't ever ask to come up to our house where he was kind of coming to an awful lot, I think you know he knew that physically he wasn't able for the journey, you know".* [435-437]

At this point, the family were becoming aware that William was seriously unwell but did not discuss this amongst themselves. The family began to visit even more regularly, and all were anxious about him;

> *F8: "And my brother [brothers name] was up and down, and we were all yeah we all kind of you know knew that William wasn't very well at that stage, but we didn't talk about it". [*65-67]

Staff stated that William knew that he was getting weaker and more tired with every passing day but did not know why. The staff did not explain it to him, and his family did not talk to him either. Elaine, when interviewed, recounted one outing with William, when they were in the car together when William told her he felt he was getting weaker;

> *F8: "I remember one day taking him for a drive and he said, 'you know', he said, 'I am very weak; I can't hold a glass you know', so he did I think know that his body […] but I never said, 'William, you know I think this is it.' And you know I regret that I didn't say, you know, well I reassured him by being there an awful lot of days with him you know and the residential home that he was in they were all really really fond of him as well, they were all mothering him".* [108-121]

Elaine did not tell William as she wanted to protect him, and the staff as stated were *"mothering him"* too. At the start of April, William continued to deteriorate. Staff assisted him to remain as active as he wanted and adjusted his diet to take account of what he was able to manage. He was given O_2 therapy whenever staff observed that he was short of breath or when he asked for this himself. William continued to deteriorate and by the end of April, staff had to hold the phone if he wanted to talk to family members. His appetite continued to diminish and both staff and his family encouraged him to eat as much as he could.

At the start of May, William was being nursed in bed and appeared frail. Staff borrowed a CD player for him, so he could listen to music in bed. He was weak and was visited by Elaine who wanted him reviewed by the GP or admitted to hospital for fluids.

5.3.8.4 The final days

Seven days before he died, William was reviewed by the GP, and it was evident that his condition was deteriorating, he was losing weight and was drowsy during the day. The GP phoned the family and talked to them about his condition. The nature of this phone call was not documented either in the nursing or medical notes, the nursing notes simply stated that this phone call had taken place. He returned to bed for the afternoon and slept for long periods over the day.

At this point, according to the data from the QODD questionnaire, staff quantified William's rate of decline as slow, and they reported that he had some symptoms such as shortness of breath, agitation and restlessness, fatigue and decreased appetite. Staff felt these symptoms were well managed and that he was comfortable and at ease. Staff did not know if he was aware that he was dying. While staff had access to, and had previously availed of, a CPCT they did not contact the service as they felt they had the expertise to manage his symptoms. Staff rated his acceptance, insight, and control as poor. They noted that no advance care plan was in place, but that

> S8 "*his wishes were expressed and documented in his care plan. They felt his wishes were met and his spiritual needs were met, and his religious and cultural beliefs were met".* [qualitative comment from SPELE]

At this point, staff felt that William lacked the capacity to understand what was going on. Six days before he died, according to his nursing notes, he appeared weak, his colour was poor, and he slept for long periods and took a minimal diet. He was visited by family and friends. Elaine, although happy that William had many friends, felt that at times he was not able for this number of visitors.

> F8: *"People were around yeah and lots of people came you know that particular week he was yeah, he was tired I think when there was so many people around and he was very unwell as well do you know just physically weak you know, just the weakness".* [411-414]

When he was alone, William slept and sometimes listened to music. Elaine felt that William was in a happy environment with people he trusted. Five days before he died William was reviewed by the GP, who advised that he be given small sips of water on an ongoing basis.

He vomited after fluids and was given Motillium[14] PR and settled for the night. The GP phoned enquiring about him and made no change to his treatment. His condition remained unchanged, he was reviewed by the GP and commenced on an antibiotic. William was only taking sips of water but appeared comfortable and slept for the night. His family remained with him.

Three days prior to his death William was difficult to rouse in the early am but then sat out for a while. He took a small amount of fluids but remained weak and slept for most of the day. He was reviewed by the GP who advised that he should continue his antibiotic and be given 0_2 if required, after exertion or if distressed. The day before William died, the GP reviewed him and friends from the ID day service visited him. On the day he died, his breathing became laboured and he became weak. He passed away in the presence of his family early in the am. Reflecting on his end-of-life care, Elaine acknowledged that the staff in the retirement home were open about the fact that William was in decline but stated that she was in denial and her emotions impacted on the decisions she made.

> *F8: "I know that clinically I could have spoken to William about his choices but as his sister emotions ruled my thinking mind".* [qualitative comments from the QODD questionnaire]

[14] This medicine is used to treat nausea, fullness, belching, heavy bloated stomach, trapped wind and heartburn which can happen after a meal. http://www.hpra.ie/img/uploaded/swedocuments/2126518.PA0823_051_002.9987a863-5ada-4ad3-8356-c69f46dc9578.000001Product%20Leaflet%20Approved.140331.pdf [accessed on the 20/9/2018]

5.3.9 Case study 9: Arthur

Arthur had a mild to moderate ID and lived at home until he was admitted to a retirement home on a phased basis. He began to stay on a respite basis at the beginning and this built up over time until he became a full time resident. He remained with the same service until he died at the age of fifty-five. His sister Noelle along with several other professionals was integral to his *"Circle of Support"* (see Figure 15).

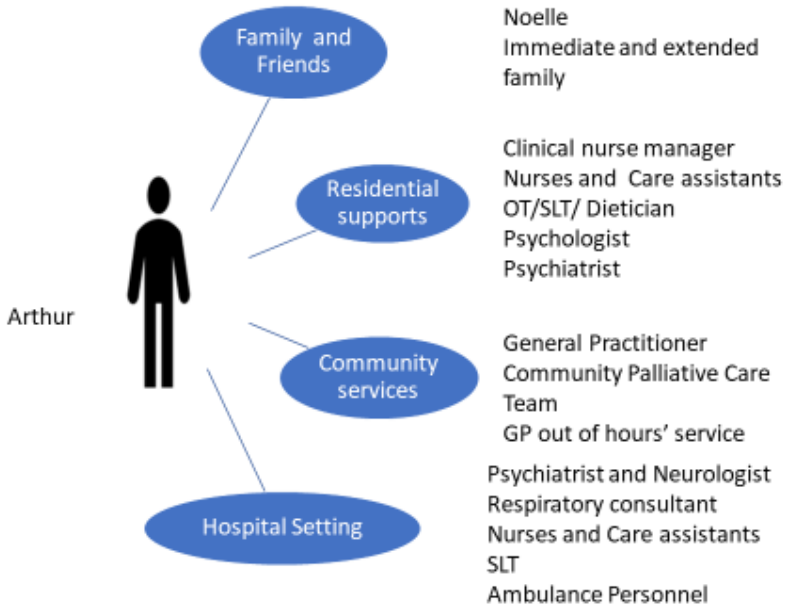

Figure 15: Arthur's Circle of Support

Prior to being admitted to the retirement home, Arthur was diagnosed with Alzheimer's dementia. His sister Noelle, when interviewed, stated that she was unsure of this diagnosis, as she felt that the agitation and anxiety exhibited by Arthur could be linked to the grief, he experienced due to the loss of significant loved ones.

> F9: "*I am never totally convinced that that was it. I think it was to me it was very much more like just a breakdown really you know".* [81-83]

Arthur was offered a place on a bereavement support group but, due to his ongoing health issues, he was unable to attend. His family knew that Arthur did not want to be in the residential home but indicated that he was also unhappy at home and, given his care needs, his elderly mother could no longer support him.

Arthur did eventually settle in the retirement home. Although he required full assistance with activities of daily living, overall, Arthur was quite well for the first year, despite having significant support needs relating to his respiratory and mental health.

5.3.9.1. Change in health status

Two years before he died Arthur was hospitalised on six occasions, amounting to a total of seventy-seven days in hospital. The data relating to these admissions was obtained from the discharge letters on file. The longest admission period was thirty-three days and the shortest was eight days. On each admission he was diagnosed with aspiration pneumonia and treated with intra-venous and oral antibiotics. On one occasion he had to be intubated and treated in intensive care. Noelle indicated that the family built up a good relationship with his respiratory consultant, who supported Arthur and ensured he was always placed in a ward, which the consultant felt, best suited his needs. However, the family regularly encountered one nurse manager who, they felt, did not want Arthur on the ward and would repeatedly tell the family that they could not cater for Arthur. Noelle acknowledged that Arthur did find hospital difficult and, at times, did not want to be on a drip. However, Noelle stated that a family member stayed with Arthur all day, when he was in hospital, and the family paid for an agency nurse to sit with Arthur each night. Noelle was cross about the attitude of the manager, and felt that given the supports provided by the family that;

> F9: *"There wasn't an awful lot asked of the staff [in terms of the day to day care of Arthur]".* [215-216]

Arthur was reviewed by the SLT in the hospital, diagnosed with dysphagia and recommendations were made to reduce his risk of aspiration pneumonia. Following one hospital admission, it was queried that PEG feeding might be an option to address Arthur's continued episodes of aspiration pneumonia. However, Noelle indicated that her mother had ruled this out as an option for Arthur because of what she perceived as the negative impact of this on Arthur's life. Arthur loved his food, and his mother did not want him to lose this as she felt it was all he had.

> F9*: "Even when my mother was alive there was talk of getting to the day where he would be PEG fed, she made it absolutely clear that that wasn't to happen you know".* [287-289]

Staff indicated that they were present when the conversation took place, between the GP, staff and his mother but nothing was ever formally put in writing with respect to PEG feeding. No documentation relating to this discussion was found in his file.

Arthur was reviewed by the respiratory consultant as an outpatient on seven occasions and was maintained on prophylactic antibiotics to keep him out of hospital as much as possible. He attended this consultant as a private patient, as having Arthur checked regularly reduced his mother's anxiety.

> F9: "*He always made it very clear to us that we didn't need to come to see him privately that he would attend to him in [hospital] but it gave my mother great comfort to have him checked and stuff like that, so we used to bring him on a regular basis".* [142-145]

During this time, Arthur was reviewed by the community psychiatric team on eight occasions to address issues relating to agitation, anxiety and insomnia. To address these, Arthur was continuously reassured by staff and treated with an anxiolytic when required. Only minimal changes were made to his medication as the psychiatrist noted that the addition of extra medications could adversely impact his swallowing difficulties. However, the psychiatrist felt that, on balance, he required some form of anxiolytic given the level of distress and anxiety Arthur experienced. These two health issues – dysphagia and anxiety continued to impact on Arthur. When he was physically unwell, his mental health issues appeared to subside, and when he physically recovered, his mental health issues would begin to re-emerge.

5.3.9.2 Change in focus of care

On the 1st of January, Arthur was diagnosed with a chest infection and treated with antibiotics and O_2 therapy. He deteriorated and was transferred to hospital where he remained for nine days. According to his discharge letter, he was diagnosed with aspiration pneumonia and treated with IV antibiotics. It is stated that he presented with increased agitation and reduced verbalization at this time and it was suggested that this might be delirium linked to his Alzheimer's disease. On return to the retirement home, he recovered well, and behavioural issues linked to agitation and anxiety began to re-emerge. He was reviewed by the psychiatrist and remained on his anxiolytic. In the month of February, Arthur presented with agitation, anxiety and behaviour issues. He attended the respiratory clinic and remained on his prophylactic antibiotic.

During March, April and May, Arthur was diagnosed with chest infections on three occasions. He was reviewed by the respiratory consultant on the 12th of May and no changes were recommended. He spent a significant amount of May on antibiotics (other than prophylactic antibiotics) and then slowly began to recover in June. During the month of June, he was relatively well but was becoming more lethargic. Overall, for the month of July, according to his nursing notes, the biggest issue facing Arthur was his intermittent anxious and agitated behaviour. He was reassured by staff and treated with an anxiolytic when required. Once again, at the start of August, Arthur required an antibiotic for a chest infection and appeared to be recovering.

However, he became chesty again, and on the advice of the GP out of hours' service he was transferred to hospital where he remained for eleven days. On admission he was diagnosed with right sided aspiration pneumonia and commenced on IV antibiotics and improved. According to his discharge letter, his resuscitation status was reviewed by his consultant in conjunction with his family and he was not for CPR in the event of cardiac arrest. He was also not for any further invasive treatment. This was discussed by the medical staff with the family and communicated to the retirement home via the discharge letter.

Arthur was anxious and agitated on return from the hospital at the start of September. He was reviewed by the GP and recommenced on his prophylactic antibiotic. He was reviewed by a dietician. Overall, he was quite well until the middle of September, when he was admitted to hospital for five days. He was diagnosed with acute bronchitis and an element of sepsis and was treated with IV antibiotic followed by oral antibiotics on discharge. He was said to be agitated while admitted and his future treatment was discussed with his family. The family queried if it would be possible to treat him with IV antibiotics in the retirement home, but the medical team indicated that this could not be facilitated. Noelle bemoaned the fact that this could not be done:

> F9: "*If he was able to have a drip for example in [the residential home] there is every chance that he would not have ended up in [hospital] and certainly not for the length of time that he did you know"* [223-225]

The medical team indicated that if he was distressed on his next admission, that the team would consider commencing him on end-of-life care. On return to the residential home, he remained on oral antibiotics for a week and during this period, he continued to be chesty. Again, as his physical health improved, he became quite anxious and agitated.

5.3.9.3 Transitioning to end-of-life care

The start of the month of October was largely uneventful. The normal rhythm of Arthur's life continued. Towards the end of October Arthur was described as *"bubbly"* and coughing up mucous overnight. He was reviewed by the GP and charted for Ventolin[15] nebs BD, with little improvement in his condition. He was reviewed by the GP again, and charted for Ventolin nebs up to a maximum of three times a day. He continued to have significant respiratory issues for the remainder of the month.

[15] VENTOLIN HFA is a prescription inhaled medicine used to treat or prevent bronchospasm in people aged 4 years and older with reversible obstructive airway disease. https://www.ventolin.com/

At the start of November, Arthur remained chesty and was reviewed by the GP and commenced on an antibiotic, and his prophylactic antibiotic was put on hold. He remained quite chesty for the next eleven days and then began to recover. During the night of the 16th of November Arthur became extremely chesty and was gasping for breath and was commenced on O_2, with no significant impact on his SPO_2 levels. The O_2 levels was then increased and the GP out of hours' service was contacted. Staff in the retirement home were advised to monitor him for an hour and then try to lower the oxygen level if Arthur could tolerate it. All of Arthur's other vital signs remained within normal limits and he was reviewed by the GP the following day and his chest was described as clinically clear. The GP met with his family and a DNR order was put in place for Arthur and signed by the GP, a family member and a witness. This took the form of a letter, on headed note paper, which stated that in the event of a medical emergency Arthur was not for CPR. Once again, Arthur recovered and did not have any significant respiratory issues for the remainder of the month.

At the start of December, a month before Arthur died, he again started to be chesty. He was reviewed by the GP; his chest was clinically clear, and he remained on prophylactic antibiotics. He continued to have audible chest crackles for the next five days and continued to be reviewed by the GP, according to the nursing notes. Arthur stabilised and remained well for the remainder of the month. He did have episodes of being agitated and anxious as he had previously done and was treated with an anxiolytic.

5.3.9.4 The final days

Eight days before he died, Arthur was wheezing and had a productive cough, according to the nursing notes. He was reviewed by the GP and maintained on his prophylactic antibiotic. For the most part, he slept for the day and his observations were stable until approximately 6 pm when his SPO_2 levels fell to 91 %. The GP out of hours' service was contacted and the doctor undertook a full assessment of Arthur. Audible chest crackles were evident, and staff were advised to maintain him on O_2 overnight and transfer him to hospital if his SPO_2 levels fell below 92%.

He commenced on antibiotics and spent a comfortable night with his SPO_2 levels recorded in the nursing notes as between 92-94%. His family were informed of his situation and the following day, five days before he died, told staff in the residential home that they would prefer if Arthur was managed within the residential home. Noelle indicated that she did not feel that she could make this decision herself; another member of the family was involved.

F9: "*They [residential home staff] spoke to us on the Monday and said you know that he was very poorly and that he was going downhill so it time to make a decision whether to put him back in to hospital or to leave him to have a dignified end I suppose in [residential home] so I just said at the time it's a decision that I am not going to make you know but I always knew what it was going to be so that was it. So, he didn't go to hospital, so he just passed away".* [254-259]

Staff, when interviewed, indicated that the final decision was left to the GP, in terms of whether to admit to hospital or not. Arthur was not involved in or informed of this decision and both his family and staff did not feel that he had the capacity to understand the issues facing him or make decisions about them. Arthur was continuing to decline and was drifting in and out of consciousness. Staff reported in the SPELE questionnaire that he was comfortable and at ease most of the time, and never appeared frightened or sad.

Staff could not speculate if he was at ease with dying and could not rate his acceptance, insight and control of his dying experience. The following day, he was comfortable, until 10pm when his O_2 levels dropped to between 87-88% and his O_2 was increased. His situation improved, but although he was treated with a nebulizer, he remained extremely chesty. His situation remained the same the following day, the GP out of hours' service was contacted for advice during the day and advised to maintain him on O_2 at 4L/min. Arthur continued to have audible chest crackles but according to the nursing notes, overall, he was comfortable, and his symptoms were well managed.

Three days before he died, his family members again had a discussion with staff in the retirement home, and a decision was made to contact the CPCT for support. It was noted in the medical notes that the GP then contacted a palliative care nurse attached to the CPCT and discussed supports for Arthur. Staff indicated that at this point, some family members who had not been consistently involved with Arthur began to visit and were shocked at the decision not to send him to hospital. There was a divide within the family and so staff were called on to bridge the communication gap between the two sets of siblings.

S9: "*He deteriorated so quickly like because they weren't in the picture you see and the other [main family members involved] were saying you [staff members] discuss with those other members [family members why the decision was made]"*. [174-178]

His medications were administered subcutaneously that day by the GP and the GP again returned that evening to adjust his medications. His oral medications were withheld at this point and, according to the nursing notes, Arthur was relaxed.

During the night and into the following day, Arthur became increasingly chesty and was suctioned and repositioned to counteract this as much as possible. Noelle was with him at the time and recalled seeing him struggling to breathe. She reported that the doctor returned to administer additional medication subcutaneously and that he settled at 6.45 am. The day before he died, the CPCT reviewed Arthur and commenced him on a syringe driver. The GP called to review him and ensure that all required PRN medications were charted. He was visited by a priest and the last rites were administered. He remained chesty, with some evidence of laboured breathing overnight but, overall, was comfortable. On the day he died, Arthur spent a comfortable day, and passed away peacefully surrounded by his family.

Conclusion

Part A of this chapter has presented the findings of this study, in the form of data relating to the organisations involved, and demographic data relating to the decedents in this study, and those individuals, both families and health professionals who formed their circles of support. The services identified in this study, are typical of the forms of residential support provided to people with an ID in Ireland. These organisations provided access to a range of ID specialist services, which were in compliance with the National Standards for Residential Services for Children and Adults with Disabilities (2013).

The nine decedents in this study had varying levels of ability and experienced a range of comorbid health conditions typically found in this population. In some instances, these individuals had spent most of their lives in their family homes and entered residential care when their health began to fail or that of their parents. In other instances, they had been in residential care since their school going years. These individuals were supported by family members, predominately siblings, who had taken over the caring role from their parents. The nine family members interviewed, had all been deeply involved in their sibling's life and close family bonds were evidenced as families spoke with emotion about their sibling and their experiences of supporting them at end of life.

A total of 16 ID staff were interviewed. They were predominately nurses providing direct care to the decedents in this study, or clinical nurse managers responsible for running the services where the decedents were supported. In the majority of cases, these ID staff had spent an appreciable period of time, in some cases decades, supporting the decedents in this study, across a range of services.

Part B of this chapter documents the nine case studies developed from multiple sources of data. Building each case study in this study, it quickly became evident that Jennifer, Johnny, Finbarr, Charles, Frank, Louise, Joanne, William and Arthur, were unique individuals, whose end-of-life stories, were very different from each other. In each case, the final two years of their lives, the supports offered to them, the manner of their deaths and where they died all varied greatly. The relationships that they had built with their families and the ID staff who supported them, also varied greatly, reflecting the bonds of close interpersonal relationships between people, be they family members or health professionals.

However, despite the uniqueness of these nine individuals, and that of those supporting them at end of life, common themes emerged across these nine case studies. Firstly, it quickly became evident that those involved, were committed to being there to support these individuals as their health failed and it became apparent, they were going to die. However, despite this commitment, those involved struggled to engage in open communication about issues relating to death and dying in general at organisational and service level. It was also evident that issues arose in breaking bad news to the individual decedents and in having conversations about end-of-life issues within individual circles of support.

It also became apparent, that while those involved in each person's circle of support were committed to providing end-of-life care, they were not always prepared for what providing this support would bring. Both families and staff, reflective of a person centred approach, remained focused on supporting the individual to maintain the natural rhythm of their lives. However, they were often slow to recognise that the person was commencing their end-of-life journey and to provide the necessary supports in a timely manner.

It also became apparent, that the decedents in this study were not included in decisions made about their end-of-life care. Medical professionals and families were mainly involved in these decisions, and staff in ID services to a lesser extent. However, in the absence of advance care planning policies or processes, it was difficult to identify how decisions were made, or the motivation for making them.

The themes identified above all impacted on the end-of-life care of the nine decedents in this study, both positively and negatively and these themes are further analysed in the cross case analysis presented in Chapter Six.

Chapter 6: Cross Case Analysis

Introduction

Of the nine decedents who died in this study, the majority died in ID residential services, two died in hospital and one died in a hospice. A wide variety of professionals, from across ID community and acute hospital and palliative care services, were involved in supporting them. Their families were also committed to being there for their loved one, as they had been throughout their lives. Having analysed the nine cases, a number of overarching themes were identified which impacted the end-of-life care and decisions made for the nine individuals involved (see Table 4). The identified themes reflected issues relating to the commitment of those involved to provide end-of-life care, communicating death-related bad news, providing support at end of life and end-of-life decision making and advance care planning. These themes and the evidence from the cross case analysis are presented in Table 4 and discussed in this chapter. In addition, these factors impacted at the level of the individual decedent, at the level of individual circles of support and at a societal or organisational level and will be described and analysed in this context.

6.1 Commitment to providing end of life care

Nationally, services for people with an ID are required to adhere to the National Standards for Residential Services for Children and Adults with Disabilities (HIQA, 2013). Limited reference is made to end-of-life care in these regulations, though the document states that those with a life threatening/life limiting condition should be able to access end-of-life care. While these national standards do not place a significant focus on the provision of end-of-life care, it is evident in this study that those involved were committed to providing end-of-life care, at an organisational level, and at the level of individual circles of support. People were supported to age and die in place and were supported in external services where this was not possible. This commitment was also evidenced in the way ID staff sought support from external services.

6.1.1 Commitment to ageing and dying in place

At an organisational level, none of the organisations involved had developed or adopted a policy in relation to providing end-of-life care leaving both service managers, ID staff, families and people with an ID, without any clear guidance or information on end-of-life issues. Despite this lacuna, the five managers interviewed, expressed a commitment to providing end-of-life care within their respective organisations. This was evidenced in the way resources were allocated to ensure ID staff could support the individual at end of life.

Table 4: Cross Case Analysis

Overarching Theme	Sub theme	Evidence from cross case analysis
Commitment to providing end-of life care *S3"It's a great privilege I think to be here, to be able to look after people"* *(176-177)*	Committed to ageing and dying in place	Managers, staff and families expressed a preference that people be cared for within ID services. This commitment required changes in organisational culture and in the manner in which services were delivered and resources were allocated. However, people had to move to other services, if their needs could not be met within the service supporting them. In two cases, decedents moved within organisations (case 4 &7) and in three cases (case 1,3 &5) they moved to external services.
	Providing supports in external services	Both management and staff expressed a commitment to supporting people at end of life in external services. However, managers indicated that these supports could not always be guaranteed, when an individual was admitted to hospital, as evident in case 9 or even when the person was at end of life (case 3). In two of the three cases (case 1 & 5) where a person was hospitalised, a formal request for support came from hospitals, to the ID service. In the case of Finbarr (case 3) supports were provided by staff in their own personal time. In the case of Arthur, (case 9), his family financed additional supports.
	Collaboration with external services	All organisations had access to GP, palliative care services, as well as hospital and hospices. There was little evidence of development of collaborative relationships between services at senior organisational level. However, across all organisations and in 8 of the 9 cases the importance of these service was identified by staff working directly with decedents in ID settings. In the case of William (case 9) the CPC team were not involved in his case as the staff did not feel they required their support for him. However, these staff did call on the support of the CPCT when required. It was clear that significant relationships had developed between staff directly caring for the decedents particularly with GP's and members of the CPCT.
Communicating death related bad news in ID services *"Everyone buries their heads in the sand"* *(1037-1039)*	Cultural Attitudes to breaking bad news	All of the families and staff interviewed in this study were Irish. Both families and staff indicated that they avoided breaking bad news. All families, apart from William's (case 8) who regretted not informing their loved one and in 8 of the 9 cases reiterated that they still would not do so, when interviewed. ID staff, although they stated people with an ID should be informed, they were at end of life, (apart from case 4) did not do so.
		Staff and managers indicated that the culture within ID services was not open to empowering staff to engage in conversations about end of life, leading to a culture of silence in relation to the provision of end-of-life care. A lack of appropriate policies and supports did not aid this situation.
	Factors impacting Breaking bad news	Issues with breaking bad news were linked to the capacity of the individuals to understand; the person's ability to communicate with their circle of support and indications that the person did not want to be informed
		Issues included a need to protect the individual involved; families and staff wished to avoid the issue of death and dying and breaking bad news themselves. The timing of end-of-life conversations also impacted on the breaking of bad news

Table 4: Cross Case Analysis (continued)

Overarching Theme	Sub theme	Evidence from cross case analysis
Providing support at end of life *"They thought she was going to bounce back again"* *(23-25)*	Maintaining the natural rhythm of life	In seven of the nine cases the rate of decline of the individuals involved was identified as gradual. In the cases of Johnny and Finbarr (case 2 & 3) their rate of decline was classed as sudden. In seven cases the decedents had been diagnosed with significant co-morbid health conditions which could potentially shorten their lives for between 1 to 5 years. However, despite these diagnoses, the focus remained on maintaining the natural rhythm of the person's life, with no evidence of discussions taking place about future care needs at the time the person was diagnosed.
	Change in care in months	A change in the focus of care of individuals from inclusion and activation in their communities to a more intensive management of health needs occurred at varying times ranging from 1 month (Jennifer, case 1) to 10 months (Joanne, case 7).
	End-of -life care begins	Recognition that a person was at end of life also occurred at disparate points on the life trajectory of individuals. In the case of Joanne (case 7) this occurred 4 months before her death and 3 days prior to the death of Johnny (case 2). Common to all cases is the fact that this recognition of the person's situation occurred quite close to their deaths in all cases.
	Staff support of families	All staff, across all cases, encouraged family members to stay with their loved one. This provided staff with an additional workload. Staff were particularly concerned for the welfare of older family members. In some instances, staff felt the person who was dying could be overwhelmed by the number of people around. Families also referred to this, but only in two cases (cases 2 & 8).
	Recognition of the role of staff	Staff, across all three organisations did not feel that their role in supporting people at end of life, was understood at an organisational level. Whilst acknowledging that senior management did not ask them to go above and beyond the call of duty, staff felt a need to be there and felt that their approach to end of life care, reflected the holistic ethos espoused by the organisations involved. However, all staff were complimentary about direct service managers, who were involved in ensuring staff had access to the required resources and were also involved in conversations about aspects of end-of-life care such as DNRs.

Table 4: Cross Case Analysis (continued)

Overarching Theme	Evidence from cross case analysis	
Decision making practices in end-of-life care *"I don't get why we wait" :(486)*	**Policies facilitating end-of-life decision making /advance care planning**	All organisations were required to adhere to the National Consent Policy, and in all cases, adherence was found in relation to everyday, service and financial decisions. However, no evidence of adherence to the policy was identified in relation to end-of-life care decision making.
		No organisation had an end-of-life policy in place but all were committed to developing one or were actively doing so. One organisation had a draft of an end of life policy developed. One service was developing a policy in relation to Advanced Care Planning. None of the remaining organisations had made a specific commitment to the development of such a policy.
	End of life decisions taken	Across all 9 cases, there was some evidence of discussion of end-of life care in medical and nursing notes, in consultant letters, and documentation from CPCT. Details of discussion were also gleaned from interviews
		In three cases, (case 1, 5 8) a DNR/NFR was not in place. In the remaining cases, these directives were in place from between 3 days (case 3) to 2 years (case 6).
		Examples of the withdrawal or introduction of treatment at end of life were found in a number of cases. In case 1 treatment for pneumonia was withdrawn and a PEG was not inserted. In case 3 treatment was withdrawn, and he was distressed and anxious. In case 7 routine bloods were discontinued. In the case of William (case 9) it was identified on his last admission, that he was for no future invasive treatment.
	Inclusion in end of life and advance care planning	No evidence of persons with an ID being included in decision making was found in files and both families and staff confirmed this when interviewed.
		Individuals involved in circles of support, were involved in decision making. In 4 cases (1,2,4,5) end-of-life decisions were made by a hospital consultant and the family, in 2 case (3, 6), the GP, family and ID staff made the decisions. and in the remaining three cases the GP and the family made decisions (7,8,9)

Where requests for additional financial support (made to the HSE to provide end-of-life care) were not positively responded to, organisations had to make up for this shortfall. In some instances, the prioritisation of end-of-life care led to the curtailment of other services as organisations managed finite resources. One manager indicated that some end-of-life resources had been financed by charitable donations.

All staff reported that additional equipment required to support the person was always provided. Resource requests from family members were also positively responded to. The main resource implications were linked to staffing. As the care needs of individuals increased, staff requirements and skills mix changed, and nursing staff were required to support these individuals.

A commitment to providing end-of-life care was also manifest in a change in the cultural ethos of organisations. As previously stated, the organisational culture within ID services was focused on promoting the independence and inclusion of people in their communities. The culture within services needed to evolve to meet the increased medical and end-of-life care needs of service users, in conjunction with their social, emotional and psychological support needs. Managers stated that cultural change was an ongoing process, and, at times, it was difficult to make change happen. However, this change did happen as services evolved to provide end-of-life care to service users.

Reflecting back on the development of these services, managers stated that organisations had developed significantly in term of providing end-of-life care. Previously, service users would have been transferred to hospital as they neared the end of their lives. Managers felt services were now more organised and committed to supporting service users to *"age and die in place"* and indicated a preference for providing end-of-life care within ID settings.

Families too, viewed the service as the person's home, as many individuals had been supported within these organisations for decades and welcomed the commitment shown by staff to support their loved one to die in place, as was evident in Johnny's case (case 2).

> F2 *"That was very important to me, that he was at home as such and we also had his funeral down there. Because like he would have been forty years left where he came from…".* [319-323}

Within organisations, end-of-life care was provided across a range of services including retirement homes, congregated community settings and small individual community houses. In the main, retirement homes and community congregated settings provided end-of-life support to a greater number of people, when compared to community houses.

Staff in small community houses, reported greater practical issues in supporting people at end of life, in comparison to other service settings. In community homes, up to six individuals could be cared for in houses located in local communities. These services were staffed by nurses and social care workers. In the main, one nurse would be on duty and responsible both for the day to day running of these services, as well as providing nursing care. These nurses would not always have the support of catering, cleaning and auxiliary services available in larger retirement or congregated settings. Providing end-of-life care, in conjunction with the diversity of roles required of nurses in these facilities, could be overwhelming. In some situations, staff struggled to provide an environment conducive to the provision of end-of-life care.

> *S5 "You are the one in the middle of it all going, 'I will be with you now, I will be with you now', and 'doctor don't forget to do that'. But then she [the doctor] walks out the door and you say, Oh [expletive] this is not done', and you run out the door after her and then the phone rings and it's a thousand other things you know. It's all just a bit manic?? and I wonder how peaceful it is for the lads who are actually dying."* [434-441]

Staff struggled with the physical environment, as these houses were small, making it difficult to accommodate the needs of the person who was dying, other service users and staff, along with family members who remained with their loved ones.

> *S2 "The bedrooms wouldn't be huge, so you might have five or six inside there, [family members in the person's bedroom with them] the heat is cranking up and people are tired you know when they are two or three nights into sitting up with somebody."* [171-175]

Staff indicated that, over time, specific services such as retirement homes came to be synonymous with providing end-of-life care. People from other services within the organisations involved, began to be sent to these services at end of life. From a positive perspective, the staff within these services began to accrue much knowledge in relation to end-of-life care and created links with community palliative care teams (CPCTs) and hospices. However, these staff spoke of the stress associated with the responsibility of constantly providing end-of-life care.

> S5 *"Sometime I feel a bit stressed out. […] but I think the responsibility, [of providing end-of life care] when it's just going on, you know it's going on now and it's not ending […] you just feel like it's an emotional rollercoaster".* [447-460]

This approach to service delivery, according to service managers, placed staff under significant pressure, due to the constant demand for end-of-life care. One manager, in particular, felt this was poor organisational policy which led to inequity within ID services and suggested more should be done to ensure staff in other services become proficient in providing end-of-life care.

This manager felt that staff in her service should have a role in upskilling staff in other services so that people with an ID could die in the place that they considered to be home, and not have to be moved to the service she ran or an acute care service, where their medical condition did not require it.

> M5 *"We don't have enough beds for all the ageing population so there are residents in [name of organisation] that are going to die in community hostels. But the way it is being dealt with probably isn't the approach that should be used, and people are panicking, and they don't know where to go with it and they are not being given clear direction".* [546-553]

Despite these issues, all staff were committed to provide end-of-life care, irrespective of the form of service involved or the issues they faced when supporting people at end of life.

> S5 *"It's a great privilege really when you think of it, it's all long term care and you see them as much as you see your family."* [322-324].

6.1.2 Commitment to providing support in external services

While all organisations were committed to providing end-of-life care in ID settings, this could not always be guaranteed. Where individuals were transferred to services internal to each organisation, the reasons were oftentimes linked to a lack of appropriate skills mix, and experience of end-of-life care within the service initially supporting the person, as was the case with Charles and Joanne (cases 4 & 7).

People were transferred to external services, when the medical treatment required could not be provided in ID settings. All of the decedents in this study, bar Charles (case 4), were admitted to hospital for IV antibiotics and fluids, which could not be provided in ID settings. The family members involved did not appear to take issue with this, apart from Arthur's family (case 9). Where individuals were transferred to a hospital or to a hospice, staff in the ID services spoke of having to *"let go "*of these individuals (cases 1, 3, 5). However, reflective of each organisation's commitment to providing end-of-life care, ID staff continued to support the decedent involved in external services (see Table 10). In the case of Jennifer and Frank, following a request from the hospital involved, staff from the ID services formally provided supports within the hospital setting. This had wage and resource implications for the ID services involved

At an individual staff level, the commitment to ensuring the person was supported at end of life was also evident, as staff spent time with the person and the family, in their own personal time, as was the case with Finbarr. Staff also spent time with Finbarr when they could be spared from their duties within the ID service.

Service managers made it clear that while all service users who required a hospital admission could not always be supported by ID staff, every effort was made to do so when the person was at end of life.

6.1.3 Collaboration with other services

ID organisations collaborated with a range of external agencies including GPs, GP out of hours' service, hospital services, hospice and CPCTs in providing end-of-life care (see Table 4). There was little evidence of coordinated collaboration with external services at senior management level of the organisations. In the main, relationships developed between ID service managers and ID staff and staff in external services. This led to the development of ad-hoc collaborative relationships, on a case by case basis, within the context of end-of-life care.

6.1.3.1 Role of GPs and GP out of hours' service

All 16 managers and staff identified the significance of the role of the GP service in providing support at end of life. One manager stated that the GP was instrumental in the development of services to provide end-of-life care. GPs generally went above and beyond what was required of them, to ensure that decedents could be accommodated within ID services, as evidenced in the case of Johnny, Louise and Joanne (case 2, 6,7).

> M2 *"They are available to us twenty-four hours a day nearly, so they are fantastic, and they are well able to provide us with advice on the palliative care input that we need".* [31-35]

It was also evident that GP out of hours' services played a significant role, especially at night. Managers, in two of the organisations, indicated they regularly availed of this service. The third organisation appeared to have little interaction with the out of hours' service as the local GP service made itself available for emergency situations.

6.1.3.2 Hospice/ CPCT support

It was evident that CPCTs were integral to the provision of end-of-life care in ID services. While all managers indicated that the support of the CPCT is essential in providing end-of-life care, managers in one organisation felt that the CPCT were particularly attuned to the needs of their service.

The CPCT established their own care plans for individuals and knew the ID service well enough to be able to identify when hands on support was required, or when phone contact would suffice. This hospice also provided end-of-life care training for staff in the service. The managers indicated that the service was contacting the CPCT team earlier in the stage of decline of individuals, so care was now better planned. This long standing relationship was also evident in a second organisation where education, on-site training, and early referral to palliative care was evident.

This level of interaction between the CPCT and ID service was not as evident in the third organisation, but the CPCT still played a significant role within this organisation. Service managers within this organisation were working to continue to strengthen the relationship between the two services.

Managers in two of the organisations indicated that ID services were too dependent on the CPCT and felt ID organisations should be more proactive in developing internal end-of-life support services.

> M5 *"And I suppose at the time before I would have come here, it was [CPCT] that were kind of doing a lot of the care, the hands on care, even the practical care they were kind of doing a lot of the medication and syringe drivers and giving huge direction to staff ".* [21-24].

These managers felt more commitment was needed to upskilling staff in ID services to provide end-of-life care in conjunction with the CPCT. However, a lack of nursing staff and the financing of on-going education were identified as barriers to this.

6.1.3.3 Hospital service

ID organisations were routinely linked to four hospitals in this study. Services availed of included out-patient, in patient, and accident and emergency departments. A variety of consultants were also involved in the care of these individuals. However, it was evident that staff in the hospitals, while committed to support people at end of life, encountered challenges in supporting people with ID. This is evidenced by the fact that two hospitals formally requested support from ID organisations for two of the three individuals who died in a hospital/hospice setting. Knowledge of the individuals and communication were identified as specific issues when supporting people in hospital.

Both families and staff felt it was important that decedents were supported by people who knew them and could communicate effectively with them, particularly where the individual was non-verbal. Staff within hospital settings also acknowledged this, in the case of Finbarr (case 3), where a request was made to the organisation to send staff to assist hospital staff with his care. Speaking of the hospital staff, Maria stated that while they were good to him, they would not have known him well enough to make a judgement as to what he could tolerate or be aware of how distressed he became in hospital.

> *F3 "It would be very difficult for them in just a short space of time to know the needs of a person like that when they can't express themselves. While I mean they are wonderful and very kind and all the staff over there were, but I think [without the ID service staff] interventions might have been done that would have made Finbarr you know, very very stressed and very uncomfortable and he wouldn't have been able to cope".* [211-219]

While linking with hospitals proved positive overall, the issues of disability bias in the hospital setting was raised in two of the nine cases in this study. Disability bias was seen to impact from both a positive and a negative perspective. In the case of Arthur (case 9), his respiratory consultant ensured that, when hospitalised, he went to a specific ward that he was familiar with. However, the nurse manager on the ward gave the family the impression that she did not want him there because he had a disability. In this instance, the family felt the need to have someone with Arthur at all times and hired agency nurses to support him by night, which involved a significant financial outlay on their behalf.

Staff also raised the issue of disability bias in the care of Johnny (case 2). Two years before he died, it was queried if an underlying malignancy was impacting on his health status. Staff felt, at the time, that further tests should have been undertaken but were not as he had a disability. Staff still held this view two year later when Johnny was admitted to A&E and a decision was made not to undertake further tests or treatment. His family, however, did not feel that this was a case of disability bias and agreed with his medical team that there was little point in continuing to hospitalise him.

Overall, both families and staff were happy with the standard of care provided to the three individuals in this study who died in hospital/hospice settings. Neither the families nor staff involved in their care, indicated that they felt their needs would be better served within ID services. However, while hospital staff were committed to supporting people at end–of-life they were heavily reliant on the interventions of families and ID staff to provide support at end of life.

Section summary

To conclude this section, it seems clear that organisations were committed to providing end-of life care, even in the absence of concrete national guidelines and in the face of funding issues. It is also evident that both staff and families were committed to providing end-of-life care irrespective of where they died and worked collaboratively together, to meet the needs of the individual. Within ID settings, staff encountered most issues in providing end-of-life care in small community homes. Despite these issues, the ID staff in these settings remained committed to providing end-of-life care. However, it is evident that not all ID residential services could support people at end of life, suggesting an inequity of access to end-of life care across organisations. It is also evident that staff in ID services were heavily reliant on GP and CPCT support, when providing end-of-life care. Specific to the role of CPCT, ID services managers felt that a greater focus was needed on upskilling ID staff in end-of life care in the face of an ageing ID population.

Where people died in external services, organisations, families and ID staff continued in their commitment to support these individuals at end of life. Organisations made their staff available to the hospital setting, and ID staff also stayed with individuals in their own personal time. While the end-of-life care of those who died in hospital was positively evaluated, it was evident that hospital staff needed assistance to provide support and heavily relied on ID staff and families.

Overall, it is evident that irrespective of where the individual died, the relationship built between the decedent, the family, and staff in ID and external services was integral to the provision of end-of-life care. Management and staff across all three organisations emphasised that good communication and mutual respect was essential when supporting people who were dying.

6.2 Communicating Death Related Bad News in Intellectual Disability Services

The issue of communicating death-related bad news in ID services emerged as a second over-arching theme in the analysis of the cases in this study. At an organisational level, no explicit reference to end-of-life care was identified in the mission statements of the organisations or in information provided to service users or their families. This lack of signposting of end-of-life services is in complete contrast to how information in relation to other services was communicated via online information, mission statements and policies. This general lack of discourse on end-of-life care within organisations, was a factor referred to by staff members and managers across all three organisations.

> *S9 "[B]ut it's like [name of organisation] as well, I don't know, they are ignoring the whole thing as well".* [1038].

Coupled with this general lack of discourse, other factors which impacted on communicating bad news were identified. These factors were both intrinsic and extrinsic to the person who was at end of life and these are considered below.

6.2.1 Factors intrinsic to the individual which impact breaking bad news

Issues relating to capacity and cognitive decline, communication, and the person's wish not to be informed, impacted on the breaking of bad news.

6.2.1.1 Capacity

As identified in the cases, staff and family members were supporting people with varying levels of cognitive ability in this study. With the exception of Jennifer (case 1), irrespective of the level of ID of the person or previous evidence of decision making capacity, neither families nor staff communicated to the person that they were dying. In the case of Jennifer, she was informed that she was ill by her family, and at end of life by the staff supporting her. Staff could not state for certain if she really understood that she was dying but, on balance, indicated that she had some insight into her situation.

In addition, even when those involved in a person's circle of support believed the person had the capacity to make decisions and indicated they knew they were unwell, as was the case with William (case 8), it did not automatically follow that they were told they were dying. In the other cases, given the level of ID of the person and their co-morbid health conditions, it could be surmised that staff and family members were correct in their assessment that the person lacked decision making capacity. However, as stated, a formal capacity assessment was only undertaken in one of the cases in this study.

6.2.1.2 Communicative ability

The communicative capacity of decedents impacted on breaking bad news. Three of the decedents, Johnny, Finbarr and Charles (case 1, 4,6) were non-verbal with the remainder communicating verbally. For those with speech, their verbal capacity was impacted over time by the plethora of co-morbid conditions they experienced. Families were particularly worried about those who were non-verbal. In a number of cases, families suspected the individual knew that they were ill or had some inkling that something out of the ordinary was going on. However, it was difficult for those involved to communicate this, and for families to understand exactly what they were trying to communicate. Oftentimes, efforts at communication took the form of fearful looks or attempts to console loved ones as was the case with Finbarr (case 6) and Joanne (case 6).

Receptive vs expressive communication concerns were also an issue. This was evident in the case of Jennifer and Johnny (case 1 & 2) whose receptive communication skills were more advanced than their expressive communication ability, i.e., they understood more than they could say. In the case of Johnny, people were afraid to say too much to him as they feared, if he were upset or worried, he might not be able to communicate that to them.

> *F2 "But you see he would be trying to get your attention and you could see that he knew what he wanted [to say] and he couldn't say it. And that was always a big shadow and a big worry because somebody non-verbal is vulnerable".* [161-163].

Throughout the cases, it was evident that families and staff continued to actively communicate with the decedents involved, reacting and responding to verbal and non-verbal communication approaches, reflecting the importance of these relationships and a relational approach to promoting the autonomy of the person involved.

6.2.1.3 Indications that the person did not want to be informed

In some instances, families stated that their past experiences with the decedents made them believe the person did not want to be informed that they were dying. The response of decedents to the loss of loved ones in their own lives influenced how families felt about disclosing a diagnosis. In two cases, that of Johnny and Frank (case 2 &5), neither showed any inclination to talk about their deceased loved ones. The families inferred from this, that neither man wished to discuss end-of-life issues, either those of other people or their own.

Staff within the ID services indicated that all decedents had previously been involved in other service users' funerals. Despite this, the decedents did not use these opportunities to open up discussions about their own mortality. However, one staff member, in the case of Charles (case 4), stated that staff did not encourage these conversations either.

> *S4: "I suppose we don't go there, and I mean that is simply the truth, like Charles saw [other service users] dying, and at that level they do understand but we never talk to them about their own mortality".* [554-557]

Therefore, it could be the case that decedents did not engage in conversations about their own mortality because they did not wish to do so. Conversely, it could also be the case that they were not encouraged or facilitated to do so.

6.2.2 Factors extrinsic to the individual which impact breaking bad news

Differing perspectives arose between staff and families in relation to informing the person involved that they were seriously ill or dying. Looking back, all family members were happy they had not informed their loved one at the time, apart from the case of William (case 8). Conversely, all 16 ID staff and service managers, bar one, indicated that the person should be informed they were at end of life. However, despite this belief, the majority of individuals at end-of-life were not aware they were dying. It was difficult to identify why this was the case initially, as no evidence was found in individual files of discussions amongst individual circles of support about disclosing a diagnosis or not. When interviewed, neither family nor staff members indicated these discussions had taken place.

In the main, staff appeared to take their cue from families and did not disclose if the family did not. Families and staff proffered varying perspectives as to why they chose not to disclose the diagnosis to the person involved including, protection of the individual, Irish cultural approaches to death and dying and the timing of conversations.

6.2.2.1 Protection of the individual

As previously stated, both families and staff wanted to protect those they were supporting from bad news. William (case 8), had insight into his health status and had told his sister Elaine that he thought he was very ill. Elaine indicated that she felt he had the capacity to understand but, despite this, her emotions got the better of her and she could not bring herself to tell him because she wanted to protect him.

Reflecting on this when interviewed, Elaine indicated that she regretted not taking the opportunity to talk to him, as she knew he did not like her making decisions for him. She wished that someone had pointed out to her, that dying is a normal process of life.

> F 8. *"I suppose there is a lot of things that need to be kind of pointed out to people you know yeah to me you know that you know it's a normal process to be dying you know".* [672-680]

From a staff perspective, one staff member in particular, who had worked with Charles for many years in a community setting, expressed strongly held beliefs that people with an ID should not be told they are going to die, as he did not want these individuals burdened with this news.

> *S4 "Really [telling them] doesn't come into it. I suppose they have had enough traumas in their life. I don't feel that they need to be burdened with that".* [559-561]

From an organisational perspective, three managers expressed the view that both families, and staff in residential services, were slow to have conversations about end-of-life issues and indicated that people with ID should be protected from this information.

> *S3 "Yeah, I had resistance from staff. It wasn't like you know, everybody was like, 'oh this is great you know, this is fabulous'. I had letters from staff stating, 'why would you be talking [about end of life] don't they have enough going on in life and now you are bringing this into their lives. And if they get stressed out now and if they are sick it will be your fault because it's you adding to their stress".* [391-394].

This manager felt this strong reaction from staff was due to a lack of understanding of what these discussions entail. Staff were more amenable to the idea when it was talked through with them, from this manager's perspective.

6.2.2.2 Avoidance of breaking bad news

In many instances, families and staff sought to avoid the issue of death and dying in general. Again, in the case of William, Elaine also stated that the family themselves avoided taking about death and dying and never discussed William's situation amongst themselves. Avoiding the topic, also underpinned the decisions of Johnny's family (case 2). Helen stated that the family had experienced a number of bereavements close together and tended to avoid talking about death.

> *F2 "But I would be a little bit for avoiding, I wouldn't want to know. I was a bit the same when the parents died and then when my sister died".* [586-588]

Management and staff felt there was an Irish cultural element to not telling the person, they were dying. These individuals indicated, as did family members when interviewed, that they wanted to avoid the issue of death and dying.

> *S1 "I think that Irish people in general shy away from this whole end of life […] I mean it's like [expletive] like we are born, we live, and we die, that's the norm, like what do you not get about that".* [442-445]

One staff member stated it was difficult to get families to talk about, or engage in, activities relating to end of life while their loved one was alive, apart from discussions relating to financial and funeral arrangements (see Table 11). In this regard, across all cases, families were quite happy to have detailed discussions about what was to happen after the person died and all had completed the end-of-life forms available, but were not willing to discuss what should happen before they died, i.e., their end-of-life care.

> M3 *"[M]aybe they have plans financially you see they are saying they have their financial plans made and you know there will be more money there to look after John or Caroline or whatever you know but they are not saying you know [anything about the person's end-of-life care]"* [579-582}

It was also evident that ID staff too, sought to avoid breaking bad news and, in some instances, felt it was not their role to do so despite the fact that they were nurses and quite happy to provide direct care at end of life. In the case of Louise, (case 6) one of the staff supporting her sought to avoid the issue by distracting her when she asked was she going to see her mammy and daddy, who were deceased. This staff member further stated that she believed that if a person were to be informed, they were dying, this should be done by the clinical nurse manager (CNM) or the doctor involved in the case.

S6 *"It takes a very skilled, like the CNM2 is crucial in that whole area as well. The doctor is number one but the CNM2 is crucial because the way they communicate to the families is very important"* [246-249]

In the case of Charles (case 4), a member of staff expressed strongly held views that people with an ID should not be informed that they are dying. While the remaining staff interviewed had all stated that the person should be informed, none of these staff had taken it upon themselves to inform the person involved.

6.2.2.3 Timing of end-of-life conversations

Staff indicated that the culture within organisations did not encourage staff to broach the topic of end-of-life care in a timely manner. This had implications in terms of the future care of individuals, leading to reactive as opposed to proactive approaches to end-of-life care.

These staff felt that delaying these conversations, negatively impacted on the ability of people with an ID and their families to engage in conversations about end of-life. This was evident in the case of Jennifer (case 1) in particular:

S1 *"Take Jennifer for example, she had [name of condition] so we know eventually Jennifer was going to lose mobility, have an increased risk of falls, lose her swallow, get recurrent whatever. So okay, we wait until she gets really sick, and then we are like, oh[expletive] now we have to deal with it, not only with her, with her family as well".* [465-470]

In one organisation, the service manager was beginning the process of engaging in end-of-life care planning in the service at the time that Louise and Arthur died (case 6&9). However, at this point in their end-of-life trajectory they were both too ill to have these discussions. Both their families reiterated this perspective expressed by the manager. In the absence of advanced care planning within the organisations, discussions were not held with decedents in a timely manner.

As described in the cases, many of the individuals in this study had co-morbid health conditions, which impacted on their cognitive and physical ability. Across the organisations, by the time decisions about end-of-life care were made, those involved, who would previously have made decisions for themselves, were no longer capable of doing so.

S4 *"I suppose it would be different if somebody got an illness where we you know, where we knew they were dying and were still aware and able to make a decision. Where I suppose our experience to date have been people have deteriorated either very quickly or their capacity has been quite diminished"*. [560-563]

Section Summary

The findings of this study suggest that the provision of end-of-life care occurred to a certain extent in silence at an organisational level, at the level of circles of support and at the level of the person who was dying, who, in the majority of cases were never told they were dying. Those interviewed identified a reluctance to discuss the topic of death and dying generally, which they suggested was reflective of Irish cultural approaches to death and dying and the culture within the organisations involved. This reluctance permeated down to an unwillingness to being involved in breaking bad news at an individual level.

In some instances, factors such as the capacity of the individual involved, and their communicative ability impacted on how information was provided to them. However, in other instances, the level of capacity of those involved was not an issue. In these cases, those involved wished to protect the individual or wanted to avoid having to break bad news themselves.

A lack of advance care planning processes also meant that, in many cases, by the time an individual's circle of support recognised the person was at end-of-life, it was too late to initiate these discussions. Given that many of the issues encountered when breaking bad news, involved issues faced by those in individual circles of support, the perspectives of families and staff supporting people will be explored in the following section.

6.3 Providing Support at End of Life

A number of people, both health professionals and family members, were involved in the end-of-life care of the decedents in this study. In the absence of organisational policies on end-of-life care, families and ID staff worked together to provide it and this support is considered under the third over-arching theme of this cross-case analysis. The sub-themes include; the importance of maintaining the natural rhythm of the person's life, change in the focus of care, the dawning realisation that the person was dying, staff support of families, and recognition of the role of staff.

6.3.1 Maintaining the natural rhythm of life

Across the nine cases, recognition that the person required palliative care, or was at end of life, occurred at differing times reflective of the person's individual circumstances. Each decedent had been diagnosed with a serious health condition in the years preceding their deaths. Despite these diagnoses, the focus remained on maintaining each individual's involvement in their communities in the face of significant health issues. For example, many of the decedents continued to attend their day services up to two to three months prior to the deaths. In the case of William (case 8), he decided for himself, that he would no longer attend his day service the year before he died, and he was the only individual with whom the issue of retirement was discussed.

Staff felt that they had to *"fight for, and along with"* the individual involved, to maintain their engagement in their communities. Staff spoke of individuals *"giving up"* and felt that they needed to continue to encourage the person to remain active until, eventually, as was the case with Finbarr, those involved resigned themselves to the fact that the person required palliative care.

> *S3 "It's a great privilege I think to be here, to be able to look after people, you know when they are well and when they are unwell, and you see it comes to that stage when you have to resign yourself to the fact that they are palliative".* [176-179]

In all cases, families spoke of their pride in the achievements of their loved ones, and how actively engaged in their lives and communities they had been. Like staff, families continued to focus on activating their loved ones, even when they were obviously deteriorating. For example, Finbarr (case 7) went out for dinner with his family six days before he died, despite it being recorded in his nursing notes that he was *"off-form, confused and hypertensive".*

Staff too indicated that families found it difficult to see their loved one decline and lose skills and access to services that their families had fought to attain. This staff member made the following comment with reference to the case of Louise (case 6), who developed dementia.

> *S6 "[I]t is almost another double whammy because you have had to fight so hard to promote independence, to get independence and then you see that being lost again".* [295-297].

However, despite the efforts of families and staff to maintain the normal rhythm of the lives of these individuals, their health needs increased leading to a change in the focus of their care.

6.3.2 Change in the focus of care

As the health needs of individuals increased, both families and staff accessed additional supports from SLT, OT, physio and nursing supports internal to ID services. Hospital services and consultants, GP, hospice, and CPCT services external to ID services were also availed of.

Eight of the nine decedents had been hospitalised for a period of time in the last two years of their lives. For those who died within ID services, the minimum number of admissions was one, and the maximum was three. The minimum amount of time spent in hospital, per admission was less than twenty-four hours, the maximum number was thirty-three days. In these cases, the majority of admissions related to respiratory and urinary infections, where IV antibiotics and fluids were required.

In the main, the ongoing care of decedents within ID services was managed by the GP, CNM, nurses and social care workers, in conjunction with family members All those involved strove to manage the changing needs of individuals. In the cases of those who died in hospital / hospice settings, their changing needs were managed by consultants and nursing staff within each hospital in conjunction with family members and staff from the ID services involved.

Other indicators that those in the circle of support began to recognise that the person was deteriorating were linked to DNR or NFR orders (some described decisions regarding resuscitation as "Do not Resuscitate" [DNR]; others as "Not for Resuscitation" [NFR]) dependent on the specific language used within each organisation. Six of the nine decedents had a DNR/NFR in place, ranging from 2 years (case 6) to three days (case 3) prior to the death of the individual. In the majority of cases, DNR or NFR orders were initiated by consultants after individuals had multiple hospital admissions and concerns were expressed about the quality of life of those involved. However, irrespective of the fact that DNR/ NFRs were in place, families and staff did not appear to realise the person was commencing their end-of-life journey.

6.3.3. Realisation that the person was at end of life

In seven of the nine cases, the rate of decline of the individuals involved was described as gradual and their deaths were expected. The deaths of Johnny and Finbarr (case 2 & 3) were described as sudden and unexpected. However, irrespective of whether the death of the person was sudden or expected, in some cases, both families and staff found it difficult to recognize that the person was transitioning to end of life. In some instances, this realisation occurred just a matter of days before the person died, as was the case with Johnny, or four months before as was the case with Joanne (case 7).

In some cases, staff did not seem to recognise that the individual was on an end-of-life trajectory, as was evidenced in the case of Johnny. In his case, both staff and his family knew he was declining when interviewed, and his decline was well documented in his nursing notes, and in correspondence with his geriatrician. Two months before he died, he required increased GP visits and had been hospitalised for IV fluids and antibiotics. However, when interviewed, staff did not consider him to require end-of-life care and were, at this point, continuing to push for active treatment. Staff did not appear to realise that Johnny was dying until two days before he died and significant issues arose in managing his symptoms. Frank (case 5) was eighty-six when he died, and while staff supporting him recognised the impact of his age and numerous health conditions, they were still shocked when he was hospitalised.

> *S5 "I just got a phone call to say Frank was unwell and I just said I couldn't believe it because when I had left, he was fine, but he was old, but he wasn't…. and they said he got quite sick…. It was very very sudden really".* [106-109]

In the case of Charles (case 4), even though his family recognised he was deteriorating over time, they only came to realise that he *"was not coming back from this"*, three to four days before he died, as was also the case with Finbarr (case 3). In the case of Louise (case 6), her sister Siobhan stated that Louise had been dangerously ill on a number of occasions, but always seemed to recover. Therefore, her death, while expected, was also perceived as sudden. This expectation that the person would recover was also evident in other cases, where the families had previously experienced the person *"bouncing back"*.

Families and staff also began to recognize the persons involved were at end of life when decisions were made to withdraw treatment. For example, in the case of Jennifer (case 1), her treatment for pneumonia was stopped and initial discussions about the insertion of a PEG were not acted on. In the case of Joanne (case 7), weekly routine bloods were discontinued before she died.

Another indicator that staff and families recognized that the person was at end of life came in the form of contact with the CPCT. In all but two of the cases, palliative care services both in hospital and community settings were involved in supporting the decedents. In these cases, the decision to involve the CPCT, occurred at times varying from days to months. In all these cases, while death might have been expected, the realization that this really was the end, mainly occurred in the last few days of the person's life.

6.3.4. Staff support of families

As families came to understand that their loved one was dying, their behaviour changed. Family members began to stay with the individuals involved, in some cases, on a 24-hour basis. This change in behaviour was triggered by conversations with staff, such as in the case of Charles (case 4). In other instances, no evidence of specific discussions with families was found, families just started to stay, and staff supported them in this.

Staff, when interviewed, were happy to facilitate families but this added to the workload of staff in ID services. In some instances, staff were supporting older family members, with significant health issues, heightening staff concerns for them. Staff were particularly concerned about the impact of fatigue and stress on older family members, especially where the death was prolonged, as was the case with Charles. While conscious of the importance of supporting families, some staff felt, that the amount of time spent with families, impacted on the level of support provided to the dying person.

> *S2: "Because do you think that having to deal with the families so intensely almost in some ways takes away from how much times that you can give to the person you are taking care of"* [791-792].

Staff, in some cases, felt that having family members present all the time, could be overwhelming for the person who was dying. For example, in the case of Johnny (case 2), staff felt, the continuous presence of all family members was a little tiring for him. Staff tried to encourage family members to take a break from the bedside, to afford the person who was dying some quiet time. In the case of William, his family recognised that he was tired and the impact that having so many family and friends was having on him.

> *F8 "[A]nd lots of people came you know that particular week... he was tired I think when there was so many people around and he was unwell as well do you know just physically weak you know,". [410-*414]

As families began to stay with their loved ones, evidence of a reciprocal supportive relationship emerged between families and staff. Staff were conscious of the emotional toll on families and tried to support them.

Families were conscious of the workload attached to supporting people at end of life and tried to support the staff. Families queried if their presence impacted on staff and were conscious of their potential to cause disruption.

> *F2: "I was always worried that we were imposing on them, that you know, my god, you know those poor girls [nursing staff] that we would be you know upsetting their flow of work or whatever. They never made us feel like that, it was totally the opposite"*. [249-253]

However, none of the families involved were ever made to feel unwelcome, apart from isolated incidents, both of which occurred in hospital settings.

6.3.5 Recognition of the role of staff

Staff indicated that their role in the provision of end-of-life care was not always acknowledged or understood at senior management level. Staff spoke of the importance of their relationship with the person who was dying and, similar to family members, felt a need to be there to support these individuals. Staff indicated that while senior management did not require them to go above and beyond the call of duty, staff felt it was important to provide the absolute optimum level of care and support.

> S4 *"You feel like you should be there all the time and you are almost on call 24 hours a day. You are not expected from the service to be on call, but you can't, because you have known this person forever more and you also know your team and you know you have to be there for them and that is something that isn't really recognised".* [438-443]

Because of the emotional toll of providing end-of-life care, staff felt that debriefing was important. In one organisation, a formal support and debriefing process was available. In the remaining organisations, this support was provided by staff to each other on an informal basis. A member of staff in one of these organisations strongly believed that a formal debriefing process should be provided for staff, especially when a person's death proved to be traumatic.

> *S2 "You see we are so involved in their lives that it becomes very intense it is nearly like one of your own. So, people have very invested feelings in the home so there is a lot of support needed for staff, especially if the end is rough".* [643-646]

This staff member, who had supported Johnny (case 2), spoke with emotion when interviewed about how difficult it was to provide appropriate support for him and her relief when staff were able to manage his symptoms. However, the nature of his death impacted on staff and caused them much distress after he died. This nurse suggested that while staff were good to offer supports to each other, formal supports were needed.

She also felt that the support provided by staff in relation to end-of-life care needed to be understood at an organisational level because this approach to care reflected the holistic ethos of the organisation involved. This staff member felt, that given the ageing population within the organisation, end-of-life care would become even more integral to the roles of staff and service provision within the organisation, into the future.

> *S4 "But I do think that it is important from a service point of view because that is part of what we are providing, it is part of our whole approach, in a holistic approach to people. This is where our population is going more and more you know and that's what the families remember and that's why the families are, in a lot of ways you know, overwhelmed by what the staff do for them, for their brother or sister".* [448-457]

Another staff member suggested that the lack of recognition of the role of staff in providing end-of life care was indicative of a lack of recognition of the issue of ageing and end of life within ID organisations in general.

Section Summary

To conclude this section, the commitment of those involved in circles of support to provide end-of life care was evident in the manner in which they actively supported the individuals in this study, when they were dying. However, despite this commitment and even when aware that the person's health was in decline, in many respects both families and staff were unprepared for what was to come. After repeated experiences where individuals "*bounced back"* having been extremely ill, it was a shock to all involved to realise that this was indeed the end.

It also resulted in additional supports such as those provided by the CPCT being accessed, in some cases, very late in the day. This led to reactive as opposed to proactive strategies in the management of individual cases.

Again, the importance of the relationships between the decedents and their circles of support were evident. Families and ID staff came together to support these individuals and evidence of reciprocal, respectful relationships between families and ID staff emerged. Providing end-of life care was an emotional experience for both families and staff, which sometimes had lasting effects. However, none of those interviewed ever indicated that they regretted their involvement.

6.4 End-of-Life Decision Making Practices

End-of-life decision making practices in end-of-life care is the fourth and final over-arching theme that emerged from the analysis of the nine cases in this study. At the outset, it is important to re-iterate that evidence was found of the inclusion of people with an ID in decision making in many aspects of their lives. These decisions were recorded in person centred plans, letters, and correspondence between the ID services, external services and families. Moreover, families and staff, when interviewed, discussed situations where decedents made decisions for themselves or were supported to do so. However, this proactive approach to decision making did not extend to decisions relating to end-of-life care. An analysis of the cases identified a number of factors impacted on end-of-life decisions including the availability of relevant policies, the end-of-life decisions taken and the inclusion of people with an ID and their circles of support in decision making.

6.4.1 End-of-life decision making and advance care planning policies

Currently, within an Irish context, as identified in Chapter Two of this thesis, the issues of capacity and consent have received much attention, with new legislation currently being enacted in the form of the ADM (2015). This legislation is informed by a functional approach to capacity assessment. Until this legislation is fully commenced, the organisations involved in this study are required to adhere to the NCP (2017) which is also underpinned by a functional approach to capacity. The latter requires that the individual involved in decision making is assumed to have capacity and an assessment of capacity needs to be undertaken should a query arise in this regard. The NCP (2017) further states that there is an onus on professionals to maximise the decision making capacity of the individual involved.

With respect to end-of-life care, families cited capacity as a reason for not including the person in decision making at end of life, with the exception of the cases of Jennifer and William (case 1 and 8). Despite these assertions, and contrary to the requirements of the NCP (2017), in only one of these seven cases (case 7) was a capacity assessment undertaken. In the case of Jennifer, despite the fact she was aware she was dying, it was documented in her nursing notes that Jennifer was not present at meetings in relation to decisions made about her care.

These findings suggest that even those with decision making capacity, may not always be included in decisions about their care, even when they have been informed that they are dying.

This finding suggests that within the organisations involved, efforts were made to ensure that the requirements of the NCP (2017) were adhered to with respect to decisions other than end-of-life decisions. However, issues arose where the person's capacity to make a decision was called into question and staff, when interviewed, made no reference to the need to undertake a capacity assessment. Staff, in the main, reported that the person was not included in decisions due to their level of ID or the fact they had a co-morbid condition which impacted on their cognitive ability. This approach reflects a status approach to assessing capacity, which has predominated in ID services and suggests that staff in ID services need support in adhering fully to the requirements of the NCP.

At an organisational level, issues also arose in relation to policies to support end-of-life decision making and advance care planning. Despite the fact that all organisations recognised that they were supporting an aging population, none of the organisations developed or adopted a policy in relation to the provision of end-of-life care or advance care planning.

Service managers, in particular, felt a lack of policies and guidance at an organisational level, inhibited cultural change as there was no strategy to educate and support staff, service users or their families in relation to end-of-life or advance care planning. Service managers felt this lack of policies impacted on the ability of people with an ID and their families to make choices about their end-of life care when they had the capacity to do so.

> M4 *"I suppose I would like to have an all-encompassing policy in place that would cover us for all eventualities and it would be lovely to have advance care directives done for people and you know to engage people in choices when they are well able you know, if they are able".* [409-414]

In addition, person centred planning processes were the main mechanism within organisations for instigating discussions about what people wanted out of life, and what was important to them. Meetings between the person, their family and staff within ID services were undertaken at least annually and a wide variety of decisions were documented. However, the person centred planning processes used within the ID organisations did not extend to include advance care planning despite the fact that the National Standards for Residential Services for Children and Adults with Disabilities (HIQA, 2013) require that where an individual wished to discuss end-of-life care, this should be done as part of this process. There was no evidence of this taking place in any of the nine cases in this study.

The lack of an advance care planning/directive process meant that opportunities to instigate discussions with people to identify their end-of-life wishes, while they had the capacity and the ability to do so, were missed. In a number of cases, comorbid health issues such as dementia significantly impacted the cognitive ability of the person by the time end-of-life decisions had begun to be made. In other cases, while the rate of decline of individuals was for the most part gradual, both staff and families seemed to be caught unawares when people began to deteriorate more quickly. In these situations, the person was too ill to have a discussion about their will and preferences for end-of life care.

It is acknowledged that senior management within organisations had begun to recognise there was a need to develop end-of-life care policies. At the point of data collection in this study, all organisations were committed to the development of an end-of-life care policy and one organisation was also developing an advance care planning policy. The impetus for the development of these policies, came from service managers, all of whom were involved in the development of these policies at organisational level.

6.4.2 Inclusion of people with intellectual disability in decision making

As identified at the beginning of this section, none of the nine decedents in this study were included in decision making. The role of advance care planning is broader that ensuring the voice of the person is heard, it requires that conversations happen amongst all pertinent parties to ensure that end-of-life care is provided in a timely and coordinated manner. In the absence of such conversations, a reactive as opposed to proactive approach to end-of-life care arises. In this study, as the decisions made in relation to the end-of-life care of individuals were unearthed through conversations with families and staff, the question arises as to what, if any, impact an advance care planning process would have made to their outcome.

Elaine indicated that she regretted not including William (case 9) as she knew he did not like having decisions made for him. Would she have responded differently, when he tried to talk to her about how ill he was, if an advance care planning process was instigated when he was first diagnosed? In the case of Jennifer (case 1) would she, if afforded the opportunity, have stated that she wanted to die in the ID service? Would her family's decision to move her to a hospice have been different if staff from the ID service had, as part of an advance care planning process, been able to offer reassurance in relation to the quality of end-of-life care and the availability of overnight accommodation? In the case of Frank, (case 5) if the independent advocate had discussed his end-of-life care with him, what decisions would he have made? While not suggesting that advance care planning is the panacea for all ills in the provision of end-of life care, in its absence, these conversations were simply not taking place.

6.4.3 End-of-life decisions taken

Through the cross case analysis, it became evident that even in the absence of policies or guidelines to support staff, families and people with an ID in end-of-life decision making, these end-of-life decisions were made. The most clearly documented decisions related to DNR/NFR orders. Two organisations recorded these orders in letters, which gave little detailed information as to why these orders were in place (cases 2, 3, 4, 6, 9).

The third organisation, specific to the care of Joanne (case 7) had a form which documented why the DNR was in place, who had been consulted and whether the person involved was aware of the DNR. This is the only example of a form, where the capacity of the person was clearly documented.

Six of the nine decedents had a DNR/NFR in place, ranging from two years to three days prior to the death of the individual. In the majority of cases, DNRs or NFRs were initiated by consultants after individuals had multiple hospital admissions and concerns were expressed about the quality of life of those involved. In the case of Johnny, (case 2) the issue of a DNR proved contentious. A DNR was put in place two months before he died by an SHO in the form of a note on a piece of paper given to the ambulance staff. Neither the family, nor the ID staff involved had been consulted in relation to this.

The fact that ID staff were least often involved in these decisions indicates a reluctance on behalf of staff in specialist ID services to become involved in end-of-life decisions where the person was supported in an ID setting. It also suggests that where hospital consultants were involved in instigating a DNR/NFR, they primarily undertook these discussions with family members without consulting ID staff. Apart from information relating to the DNR/NFR orders, additional information was found in the files of the individuals involved. However, in the main, the majority of the detailed information relating to end-of-life decisions was gleaned from interviews with families and staff and the questionnaires used in this study.

In the absence of specific protocols or end-of-life care forms to document decisions, information was mainly recorded in nursing notes, medical notes and hospital discharge letters. Mostly, information in the files was specific to the medical care of the person, predominately, in relation to symptom management. However, little information was found in the files about how end-of-life decisions were made, and this mainly related to the withdrawal of treatment. For example, reference was made to the insertion of a PEG in the case of Jennifer, which did not then proceed. There was no information provided as to why a PEG was initially suggested or why it was not inserted.

A little more information was provided in the case of Finbarr (case 3) where treatment was withdrawn as it was futile, and he was distressed and anxious. Overall, his family felt that his quality of life was very poor and did not want him to receive any further treatment. However, references to decisions made were vague and mainly referred to phone calls or discussions with GPs or hospital staff, that were documented in nursing notes.

Most of these nursing notes simply referenced that a discussion had taken place, providing few details as to what was discussed and by whom. Across the cases, it is evident that important discussions were taking place, but no evidence of who was involved and the decisions made were found.

In some cases, no written documentation of important decisions was found at all and that these decisions were made only became apparent during interviews with families and staff. This is evident in the case of Arthur, where the decision not to insert a PEG was not documented anywhere in his file. Despite the limited documentation of decisions made, it is evident that a wide variety of people within circles of support were involved in making decisions on behalf of decedents. However, the nature of and the motivation for making these decisions was not recorded. Additionally, the outcome of many discussions was not clearly recorded.

6.4.4 Influence of circles of support

As identified in the nine cases, along with family members, an average of fourteen professionals were involved in supporting each decedent. These individuals were involved in decision making to greater or lesser extents, dependent on the case involved and where the person was cared for at end of life. The influence of families will first be discussed, followed by that of staff from the ID specialist services.

6.4.4.1 Families

It is important to note that the majority of family members who were making decisions were siblings of decedents who took on the role of carer, previously fulfilled by their parents. In the case of Frank (case 5), his sister-in-law Emma took on the carer role from her deceased husband. Whether still alive, as was the case with Jennifer and Charles (case 4), or deceased, the person making decisions on behalf of decedents was influenced by those who had previously fulfilled the role of carer. This factor emerged during the interview process where family members spoke of the influence of others and the need to respect their wishes.

In some cases, the influence of others determined the decision made, as was evident in the case of Arthur (case 9). His sister Noelle stated she would never go against the wishes of her (deceased) mother. In other instances, their influence was subtler as families sought to fulfil promises they made to the parents, to protect their siblings, as was seen in the case of Charles (case 2).

> *F2 "They went to their graves like worrying about him, not worrying about him as such to the extent that they were or that they used to but needing reassurance from us that he would always be ok, because we were always looking out for him".* [565-568]

Therefore, in a number of cases, the decision maker in the family often times became a conduit for the decisions of others who had previously been the main support to the person involved.

The decision making role of families varied to a greater or lesser extent, though all families were involved. In most cases, one person took on the central decision making role; in the case of Jennifer (case 1), two of her sisters were equally involved. In some instances, not all families had ongoing contact with the decedent and relationships between siblings could be frayed causing relationships to break down, as was reflected in Arthur's case (case 9). Here, ID staff adopted a liaison role, communicating and supporting both sets of family members in as impartial a manner as possible.

Families indicated they did not plan ahead, not just in relation to end-of-life, but, in relation to all aspects of the care of their loved one. According to families, there was little opportunity to plan ahead as they did not know what, if any, services would be available in the future. For example, in the case of Louise (case 6) and William (case 8), these two individuals were admitted to residential care at a time of crisis, following a hospital admission, or, when their health needs increased.

> *F2 "For people nowadays, you see people have, they can pre-plan things and there was no plan for Johnny, you see that was his biggest loss, I mean he had never been anywhere or anything or part of a group or part of anything, only part of our family".* [553-557]

Families learned to manage situations as they arose and make decisions as they went along. Families, through person centred planning processes, were used to being involved and consulting with staff in ID services, once their loved one was in residential care. However, as previously stated, this process did not extend to end-of-life care or advance care planning, apart from the documentation of religious beliefs and funeral arrangements.

Families were influenced by GPs and medical staff when making decisions for the decedents. In six of the nine cases, the decision to commence an individual on an end-of-life care plan was taken by consultants or SHOs in acute care settings. The decision that individuals were no longer for aggressive treatments and were for comfort care only were made by hospital staff and the families involved. These decisions were then communicated to staff in the ID services involved. In the remaining cases of Charles, Joanne and William, (case 4,7,8) the GP talked to the families involved in relation to their care needs.

In some cases, there was evidence of effective consultation between families and the health professionals involved, as was the case with Finbarr (case 3). The decision to withdraw treatment and commence him on end-of-life care was initiated by his family, who requested that no further investigation be done on the basis that he was frightened in hospital and would become distressed when in pain. A DNR was put in place at this time based on a poor projected quality of life.

Frank (case 5) had bowel surgery the week that he died and was in pain post-operatively. Emma, unhappy with his care, began to question the level of pain relief provided and insisted more be done and the palliative care team became involved. In the afore-mentioned cases, family members were proactively involved in decision making.

However, this did not apply in all cases, as evidenced in the case of Johnny (case 2). His sister Helen, indicated that the family were not involved in decisions about his care per say, instead indicating that ultimately decisions were made by the medical staff and the family were *"informed".*

> *S2 "We met the consultant and you know like we were informed; I think at all times to be honest!".* [517-519]

This was also the case, when Johnny transferred back to the ID service prior to his death. Helen consistently reiterated that she was kept informed and alluded to her reliance on staff to make decisions for, and provide support to, Johnny. However, it came to light during the interview that the family had not understood everything. Helen, when interviewed, asked what dementia was, and did not seem to understand what palliative care was.

> *F2 "They explained everything but then we didn't understand everything as such you know there would be aspects of it that we wouldn't have known. Palliative care, what does it entail do you mind me asking? "[*342-346]

The family did not feel the need to know everything about Johnny's care or make all the decisions. It was clear that they trusted the professionals supporting him to make the right decisions. Once he was not in pain, the family were happy to hand over decision making to the staff caring for him and seemed happy to be *"kept informed".*

Therefore, it can be seen, that while all families were involved in discussions in relation to the end-of life care of their loved ones, their actual input varied greatly across services. Of most concern is the evidence that, in some instances, family members were party to decisions where they did not fully understand all the information provided to them.

6.4.4.2 ID staff

In the main ID staff were heavily involved in the provision of end-of-life care and it was evident that staff in ID services made many clinical decisions at the bedside as they cared for the decedents involved. However, these staff did not engage in conversations about DNR or NFR, or Advanced Care Planning, apart from CNM level.

In this context, ID staff had many conversations with other staff members internal and external to services, especially with GPs and CPCTs as they provided this hands on care. For example, in the case of Joanne (case 7), her care plan was constantly updated as she progressed towards end of life. However, the nurse supporting her referenced the fact that there was no advance directive in place and that the staff were managing the situation as they went along.

> S7: *"There was no directive from [name of organisation] you know about what we should do it was basically left to us as nurses you know you make the call like, you are there, you make the call."* [89-94].

There is evidence of ongoing interaction between ID staff and families which intensified as the person began their end-of-life journey. Staff indicated, when interviewed, that they knew advance care planning should be occurring well before the person began to decline. However, in the absence of advance care planning policies and processes, a day to day approach to clinical decision making was adopted in conjunction with the GP, as the person deteriorated.

> *S5 "Look you know you need to have conversations with them, and we do that when we have it all documented but no directives really just the doctor would document the DNR and that they had a conversation with the family, with the staff present you know. So, it just depends on the clinical decision on the day".* [567-572]

ID staff did not always feel they should be the one to become involved in having these conversations. For example, in the case of Arthur (case 9), ID staff indicated that they did not want to become involved in decision making discussions because of long term disputes between families, which could lead to acrimonious situations, which had to be handled in sensitive and pragmatic ways. Staff did not want to be seen to be taking sides in such situations.

> *S9 "They [two siblings] were looking in two opposite directions like, they were both looking at those[walls], she was looking at one wall and he looked at the wall next to him, looked at it and the doctor in the middle talking like and. They couldn't engage".* [183-187]

In some instances, ID staff did not want to engage in conversations about advance care planning and felt these should always be undertaken by the clinical nurse manager in charge or the GP. This perspective is also reflected in the tendency of these staff to avoid breaking bad news to the person they were supporting. In keeping with this perspective, one CNM indicated that, from her experience, staff were reluctant to engage in these conversations with families and, therefore, responsibility for having these conversations fell to nurse managers.

In the main, as previously stated in this section, conversations relating to end-of-life decisions occurred between consultants and GPs and the family members involved. Staff in ID services were not seen to engage in these conversations irrespective of where the person involved died. One manager in an ID service stated that consultants and GPs were best placed to engage in advance care planning and end-of-life decision making although she did not feel that ID staff should not, or were incapable of, having these conversations. She simply felt that families accept being told that their loved one is dying more readily when told by a consultant than when told by nursing staff in ID services.

> M5 *"A family is going to believe a consultant before they believe the nurse, you know, and that's there and that's always going to be there for you know,"* [374-376]

It was also evident that staff in ID services did not engage in end-of-life or advance care planning conversations when decisions were made in hospitals about people they cared for. For example, in the case of Jennifer, the staff from the ID service were waiting for a discharge plan, assuming she was returning to the ID service when, in fact, the decision had been made between the family and the consultant that she would be moved to a hospice.

Towards the end of Johnny's life (case 2), staff from the ID services felt excluded from decisions made and believed that the hospital staff had the final say, in conjunction with his family, even though they were the individuals required to provide this care.

> *S2 "I suppose as regards his care like we didn't have a massive amount of input, the hospital initially decided this is as far as we are going. We are handing him over to you and you manage him conservatively".* [211-212]

It is apparent from the nine cases, the ID staff play a prominent role in providing end-of-life care, irrespective of where the person involved died. They also play a central role in supporting families. However, despite the importance of their role in supporting people at end of life there is little evidence of their involvement in making significant end-of-life decisions.

Section Summary

To conclude, people with an ID are not included in end-of-life decision making. In the absence of advance care planning policies or processes, it is difficult to identify how decisions are made, or who is making them. The majority of decisions clearly documented were in relation to medical care, such as DNR/NFRs, or withdrawal of treatment.

The will and preferences of the decedents in relation to their end-of-life care was not documented anywhere in the case files. Both families and staff stated when interviewed, stated that discussions were not held with the individuals involved about any aspect of their end-of-life care, be that in relation to their medical care, or the social, or spiritual aspect of their care, or where they would like to spend their final days.

A wide variety of people in the circles of support of individuals are involved in making decisions which are primarily made by medical staff and GPs in conjunction with families. While playing a pivotal role in providing end-of-life care, ID staff play a limited role in decision making overall. Both managers and ID staff identified the need to make decisions about end-of-life care in a timely manner. However, in many instances, this did not occur, and end-of-life decisions were made in the final phase of the person's life.

Conclusion

The nine decedents in this study were all unique people who were supported by distinct circles of support. They died in a variety of community based and acute hospital and hospice settings. Across the trajectory of their end-of-life journey they accessed a range of resources and relied on the support of their families. They also encountered a range of professionals; some encounters were fleeting, others spanned decades. Despite the obvious individuality of each case, this cross-case analysis has identified common themes which impacted on end-of-life care and decision making at organisational levels, at the level of families and staff, and at the level of the descendants.

These themes reflected the commitment shown at both an organisational level, and at the level of individual families and health professionals, to supporting these people at end of life. A commitment was shown to supporting people to age and die in place, but not at the expense of impacting access to appropriate end-of-life care. In order to ensure that people had access to appropriate care, service managers, in particular, sought to develop links with external services and worked to establish collaborative relationships across acute and community based services. They also sought to develop appropriate services within their own organisations and to develop polices to support the provision of end-of-life care.

Despite the commitment shown, those involved encountered issues that impacted the end-of-life care of the decedents and decisions made on their behalf. It emerged that communicating death related bad news was an issue which all involved struggled with. Irish cultural attitudes and organisational cultural ethos appeared to impact on the breaking of bad news. There was a reticence to communicate about death and dying in general, and end-of-life care in particular, amongst those interviewed. In some cases, those involved actively avoided these conversations. Factors intrinsic to the person, such as capacity, communication issues and a belief that the person did not want to know were all found to impact. Factors extrinsic to the person such as families' and staff's need to protect the individual, families and staff wanting to avoid the issue themselves, and the timing of these conversations were barriers which needed to be overcome.

In the main, families and ID staff focused on maintaining the natural rhythm of the person's life and supporting them to actively live it. However, eventually, due to the increased health issues they experienced, their focus of care changed. In many instances, this happened quite close to the death of the individual as those involved did not always seem to recognise that the person was dying or expected them to bounce back as they had done before. Families too needed support at this time and relied on ID staff for this support. ID staff were committed to supporting the person and their families. However, these staff felt their efforts were not acknowledged at an organisational level.

With respect to decision making at end of life, this cross case analysis identified that people with an ID are not included in decisions making. Organisations lack policies and processes to support staff and family members instigating advance care planning. Therefore, the voice of the person is lost, as opportunities to identify what they might want at end of life are squandered. The majority of decisions made are medical decisions relating to DNR/NFR orders and withdrawal of treatment. These decisions are predominately made by medical professionals and families. While, in the main, decisions are documented, little is known about how these decisions are made or the motivation for them as the information recorded is scant.

Having identified the common themes that thread across these nine cases, a discussion of these is presented in Chapter 7 in relation to the relevant literature in this area. These themes, which include the level of commitment shown to providing end-of-life care, issues communicating death related bad news, providing support at end of life, and end-of-life decision making will now be discussed in chapter seven of this study.

Chapter 7: Discussion

Introduction

This chapter draws on the literature reviewed in the early chapters of this thesis, as well as other relevant literature. This literature is used to contextualise and critically discuss the findings and insights from the cross case analysis focusing on four themes: the level of commitment shown to supporting people at end of life by the relevant parties identified in this study; providing support at end of life, communication of death related bad news and end-of-life decision making. The implications of the findings of this study are also presented along with the strengths and limitations of this study. This chapter concludes with a synopsis of plans for disseminating the findings of this study.

7.1 Commitment to Providing End-of-Life Care

A commitment by those involved in individual circles of support and across community and acute services to support people with an ID at end of life, is very much in evidence in this study. All specialist ID services and people in individual circles of support, be they family members or health professionals, were committed to facilitating people to age and die in place and being there to support people at end of life. Despite this commitment, those involved encountered issues in relation to their level of preparedness to provide end-of-life care in conjunction with factors relating to consultation and collaboration between services.

7.1.1 The importance of being there

The importance of circles of support being there to support individuals with an ID was evident, not only while the person was dying, but in many instances, over decades. Circles of support were of importance for two specific reasons. Firstly, the nine decedents in this study, were quite dependent on their circle of support, as their health declined. Secondly, these circles of support had amassed a substantial amount of information and insights into each individual, which proved invaluable in providing person centred care for those involved.

Circles of support were imperative to ensure the needs of the decedents in this study were met at end of life. All of the nine decedents, not only experienced all the issues faced by the neurotypical population, they also faced additional issues specific to people with an ID. As previously stated, all decedents in this study experienced significant cognitive decline in their last two years of life, sometimes at an accelerated pace with respect to those with down syndrome and dementia. They also developed epilepsy and had a variety of health conditions, which impacted on their physical ability which was also seen to decline.

Coupled with this, were the communication issues which these individuals experienced, which impacted their ability to understand what was happening to them and to make themselves understood. This was compounded by the communication deficits experienced by those supporting them, as they continued to engage with these individuals.

The wealth of knowledge that members of these circles of support had built up over the years was instrumental in decisions made as these individuals began to decline and become more dependent as they transitioned to end of life. In the majority of cases, each individual was supported by family members and staff in ID specialist services for many years, reflective of patterns of support identified in other studies (Todd et al. 2013; Ryan et al. 2011). Those in these circles of support were heavily involved in the development of person centred plans with each individual. Evidence was found of efforts made to support these individuals to make decisions and have control over their lives, reflective of relational approaches to autonomy and capacity. There was evidence of collaborative relationships between families and ID staff that had built up over years, and the importance of these relationships was evident when these individuals required end-of-life care.

As identified in the cross case analysis, a person centred approach to including the person in decision making, did not extend to decisions in relation to end-of-life care. However, a relational approach to autonomy, discussed in Chapter Two, was evident as families and staff drew on their collective knowledge regarding these individuals, when supporting the person at end of life and making decisions on their behalf. Across all cases, families and ID staff referred to previous experiences with these individuals, their knowledge of what the person liked and disliked, what they would and would not tolerate. Those within the circles of support used this information to advocate on behalf of those with ID. The members of individual circles of support were respectful of those they were supporting. None of the family members or ID staff made assumptions about what the person would have wanted. All those involved openly admitted that, in some situations, they were not entirely sure what the decedents themselves would have wanted. Instead, they made it clear, they were doing the best they could, to provide the kind support and make the kind of decisions they felt that the person would want, based on what they knew about these individuals.

While it is important not to conflate the views and perspectives of people with an ID and the families and ID staff supporting them, it should be acknowledged that their circles of support worked together, and used their collective understanding of the individuals involved to ensure their end-of-life needs were met. Therefore, these circles of support were instrumental in supporting people at end of life.

7.1.2 Ageing and dying in place

The commitment of both organisations and people in individuals' circles of support, to provide supports to an emerging ageing population, is clearly demonstrated in the cross-case analysis of this study. All involved were committed to supporting people at end of life irrespective of where the person died. A commitment to support people to *"age and die in place"* was seen in all organisations. Residential services were either developed, or adapted, cognisant of the changing needs of an ageing demographic in ID services. That these organisations embraced the concept of aging and dying in place is not unique, as this approach to service delivery has been identified in previous Irish studies and, internationally, in both the UK and the Netherlands (McCarron et al, 2010; Todd et al. 2013; Bekkema et al. 2014).

Six of the nine individuals in this study died in ID services, in retirement homes, community group homes and small individual community houses. Staff in small community houses reported facing the greatest number of challenges in relation to providing end-of-life care. In two cases in this study, the individuals had to be transferred from one community service to another to ensure their increasing health needs could be met. These individuals were transferred to services with a higher compliment of nursing staff, suggesting that the skills mix in some community houses were not conducive to supporting people at end of life. That questions arise as to the ability of certain community homes to support people with an ID at end of life, has also been established in another Irish study (McCarron et al. 2015). However, as evidenced in this study, where appropriate resources and clinical supports were provided within specialist ID services, in conjunction with those provided by outside agencies such as CPCTs and GPs, staff within community homes could provide end-of-life care and were committed to doing so. Providing these resources ensured people ended their lives in their homes, supported by those who knew them best.

All those involved, both families and ID staff focused on the individual, reflective of the holistic, person centred ethos of the organisations involved. Members of the multi-disciplinary team, both internal and external to the organisation involved, worked collaboratively to provide end-of-life care. The importance of having access to appropriate resources and staff with the correct skills mix has been identified by McCarron et al. (2010) and, as is evident in this study, can ensure that these services are capable of providing optimum end-of-life care.

However, this study has identified, by virtue of the fact that people had to be transferred within organisations in order to receive appropriate end-of-life care, that not all community homes currently have the capacity to provide this support. This suggests that an inequity of access to appropriate end-of-life care may exist within ID services.

Service managers also alluded to the fact that, in some cases, people with an ID had to be transferred to hospitals not because of the complexity of their medical needs, but because they could not be accommodated within the organisations involved. While not the case for the decedents directly involved in this study, managers did indicate that this was an issue in certain community based services. This is a concern since, at a national level, a policy of decongregation is being rolled out (HSE, 2013), which involves the movement of people with an ID into community homes. It is therefore imperative that community services are capable of providing end-of-life care for the burgeoning ageing population who will require this support.

Despite the preference for, and commitment to, supporting people with an ID to *"age and die in place"*, neither management nor staff believed that supporting the person to die at home should take precedence over providing appropriate end-of-life care. In this study, three people were transferred to hospital when their medical needs were beyond the remit of the service the organisations provided. The main issues arose in relation to the provision of IV fluids and antibiotics. The specialist ID services involved sought professional medical advice as to the feasibility of providing this medical care within the ID service. However, all were advised that this form of support was best provided in a hospital setting. Whilst other studies have identified issues in providing this form of clinical care (McCarron et al, 2010; Todd et al. 2013; Bekkema et al. 2014), this study is one of the first to highlight efforts made by service managers to expand the clinical support provided, to beyond what would be considered typical for these forms of services. It speaks to a commitment to make every effort to meet service users' needs on behalf of these organisations. Of note, is that where the two organisations involved sought advice on providing IV antibiotics and fluids, both of the managers involved had engaged in further education in palliative care and gerontology, and were passionate about expanding services to people at end-of-life, to ensure they could be supported in their own home.

Staff and management, when interviewed, stated they found it difficult to *"let go"* of individuals and transfer them to external services, a perspective also identified in previous Irish studies in Ireland and the UK (Ryan et al. 2011; Todd et al. 2013). However, in contrast to the findings of Todd et al. (2013) who found that hospital deaths were perceived as *"failures",* ID staff in this study did not express this view. It could be surmised, that the families and staff in this study did not view hospital deaths as failures because these individuals never really *"let go"* of the people they supported. Those involved in individual circles of support, continued to be instrumental in providing end-of life care either on a formal basis at the request of hospitals or, informally, by showing their ongoing commitment in their own personal time.

ID staff in this study seemed, in the main, despite reported incidents of disability bias, to be positively disposed to how end-of-life care was provided in hospital settings. That staff and families who have been facilitated to continue to care for and maintain their relationship with people at end of life, view hospital deaths in a more positive light, has also been identified in UK and Australian studies (Todd et al. 2013; Wiese et al. 2012).

7.1.3 Preparedness

Whilst the commitment of services and individual circles of support to providing end-of-life care was evident, questions arise as to how prepared all those involved were for what lay ahead. The issue of preparedness manifested in a variety of ways, across the disparate services responsible for providing end-of life care. Within the hospital setting, there appeared to be a lack of preparedness to care for people with an ID.

To be clear, being cared for by those who know you, especially when fearful and requiring reassurance, is to be expected. Even when people with an ID spoke highly of hospital staff, as found by McCarron et al. (2018), they still expressed a preference to be supported by those who understood their needs well. However, there is a distinction to be drawn between people within individual circles of support, staying with the person because it is their preference and requiring them to be there to augment the services provided by staff in these settings.

It is evident in this study, that hospital staff encountered issues supporting people with an ID since in two of the three cases where people were hospitalised at end of life, they requested the support of staff from specialist ID settings. In the third case, while not formally requested, families and ID staff spent an appreciable amount of time with the decedent involved, and one family paid for the services of an agency nurse at night. Acceding to these requests had resource implications for ID services and took an emotional toll and, in some cases, a financial toll on families.

Issues identified included hospital staff's level of knowledge of rare syndromes and ability to communicate effectively with people who were non-verbal. The issue of disability bias was also referred to, where hospital staff were described as overly focused on the fact that the person had a disability. Where ID staff were available in hospital settings, the day to day care needs of these individuals were met by ID staff. It seems unlikely that hospital staff will gain experience in providing care to these patients, as long as this continues to be the case. The evidence in this study, that inpatient hospital services, struggle to support people with an ID, and are not fully resourced to do so, is also reflected by the fact that the development of hospital liaison roles for RNIDs within the acute hospital setting has been identified as of importance nationally (McCarron et al. 2018).

The issue of preparedness, also arose in the ID setting in relation to providing end-of-life care, linked to organisational cultural ethos and staff education. The fact that some services had a strong social model of care ethos meant that staff in ID services focused on the activation and integration of people within their own communities. This approach is paramount in ensuring people live long, fulfilled lives, and people with an ID themselves have identified the importance of continuing to live their lives when faced with a terminal diagnosis (McKenzie et al. 2017; Bekkema et al. 2016). This principle of continuing to live one's life, until the end of life is also paramount in the provision of end-of life care according to Cecily Saunders (1993).

However, in this study, the continued focus on activation and maintaining the natural rhythm of people's lives, led to a lack of preparedness for what was to come. ID staff were aware that individuals had life-limiting conditions and diagnoses such as dementia, which would impact their decision making capacity. Some of these individuals were hospitalised multiple times and both families and staff referenced the fact that they knew these individuals were declining. However, despite this knowledge, little advance care planning was done, apart from the instigation of DNRs and NFRs in some cases. This lack of advance care planning, unsurprisingly, led to reactive as opposed to proactive approaches to care, an issue which both Ryan et al. (2012) and Wiese et al. (2012) have also identified. However, when issues arose and people required end-of-life care, ID staff rose to the challenge and accessed supports that were instrumental to meeting the care of individuals, such as the medical support of GPs and the palliative care support provided by CPCT. Resources and equipment that were required, were provided, but this led to highly pressurised situations which in some instances, left staff with a feeling of disquiet, about the end-of-life care provided to the individual involved.

Another reason for the lack of preparedness evident in these cases is linked to issues in end-of-life care training and education of staff. In some instances, neither families nor staff appeared to recognise that the person was at end of life. This meant that CPCTs only became involved in the care of individuals, in some cases, in the days just prior to the person's death. In some instances, this left ID and CPCT staff struggling to control the complexities of their care. That staff in ID services struggled to recognise when a service user was at end of life, is also reflected in the findings of McCarron et al. (2018) who also found that CPCT referrals occurred very late in the day.

Both managers and ID staff in this study identified the importance of the role of the CPCT and it was evident that ID staff relied heavily on their support. Managers indicated that services were over reliant on the support of these services and felt that staff in ID services should be better educated in end-of-life care.

That managers and staff identified an over-reliance on CPCTs by ID staff, suggests that little has changed in terms of addressing the educational needs of ID staff in the intervening decade since Ryan et al. (2010), identified issues in this area, within an Irish context.

However, the fact that ID staff have become over-reliant on CPCTs' support, can also be viewed from a positive perspective as it indicates an increased interaction between palliative care and ID services. This suggests that people with an ID have improved access to specialist palliative care, as previous research had indicated that people with an ID do not habitually access these services (Bailey et al.2014; Tuffrey-Wijne et al. 2007;2008). On a further positive note, it was also identified in this study by service managers that members of the CPCT were providing on-site education as they cared for individuals at the bedside, indicating that efforts are being made to upskill staff in ID services. Having said that, the ad-hoc manner in which this is done, was service specific as opposed to occurring at an organisational level. Therefore, the preparedness of ID staff to provide end-of-life care may not be consistent within and across ID organisations.

7.1.4 Consultation and collaboration

Given that people with ID are cared for across multiple services, with the input of a range of professionals, the need for consultation and collaboration is evident. Within the ID services, there was evidence of cooperation and collaboration, most specifically with respect to GPs and the CPCT. As previously stated, the CPCT were available to staff in ID services, although for a much shorter time than that of GPs in individual cases. However, in these instances, the level of collaboration and consultation was intensive as ID staff and CPCTs worked together to make each individual as comfortable as possible. It was also evident that there was ongoing collaboration and consultation between the GPs involved and the CPCT.

Across a number of cases, it was evident that there was ongoing interaction between GPs and ID staff in ensuring that people could stay in their own homes. ID staff consulted with GPs when they had concerns, and GPs made multiple visits in a week or even a day if required. These findings are echoed by McCarron et al. (2018) who also identified that staff in ID services felt that people with an ID had very good access to GPs and that GPs were respectful of service users. Central to this day-to-day collaboration was the level of respect and understanding of the needs not just of the person, but the ID staff and the service. For GPs, the provision of end-of-life care extended beyond caring for the person. They were called on to inform families of the person's situation but, interestingly, there was no indication, in any of the nine cases in this study, that the GP suggested or tried to have a conversation with the decedents involved. This was also the case with respect to hospital consultants.

While it is not clear, as GPs were not interviewed in this study, as to why GPs did not engage in such conversations, other national and international studies suggest that GPs do not engage in these forms of conversations with people with ID because they do not feel that those involved would have the capacity to understand their diagnosis, irrespective of their level of ID (Wagemans et al. 2013 a).

While no significant issues were identified between community services and ID services with respect to consultation and collaboration, issues did arise within and between hospitals and ID services. There was evidence of ongoing correspondence between consultants involved and ID staff, from information in the person's file and the interviews with staff. There is also evidence of ongoing interaction between consultants and families who, in many instances, had collectively managed the health needs of decedents over many years. However, there were also instances of poor consultation and collaboration, where ID staff felt that hospital staff conferred solely with family members and excluded them, even when they were providing supports within the hospital setting.

ID staff felt that decisions were made in hospital settings and the person was then discharged to them for conservative care without any consultation or collaboration. In one case, the staff from an ID service were awaiting a discharge plan for a service user, only to find the decisions had been made with the family, to transfer her to a hospice. That ID staff felt disenfranchised and excluded in these situations is reflected in the findings of studies in this area, which have identified that medical professionals attributed more weight to the opinions of family members when making decisions than that of the person with the ID themselves or ID staff (Wagemans et al. 2013a; Bekkema et al. 2014).

One of the five managers interviewed in this study, reported that they had established good links into a local hospital with a number of consultants in particular hospital departments, who regularly engaged with service users. Networking in this manner, appeared to assist in the development of better collaborative relationships. However, no other manager or staff member indicated they had established such links suggesting that collaborations at this level are the exception as opposed to the rule, a finding with which McCarron et al. (2018) concur. The importance of better integration between health and social care services, has also been identified at a national level in Ireland. The Integrated Care Programme for Older People (ICPOP), initiated in 2016 by the Health Service Executive, has developed a 10 step framework, to better integration of health and social care services, and continues to work to achieve this.

To conclude, the commitment of those within circles of support to providing end-of-life care is evident. However, all involved encountered issues in providing support to decedents in their care. Hospital staff encountered issues in meeting the needs of people with an ID.

Conversely, staff in ID services did not appear to have the experience to support people at end of life. This lack of preparedness impacted on all members of the circle of support as people reacted and responded to the changing needs of the individuals involved.

A second issue was identified in relation to the level of consultation and collaboration between community services such as the GP and CPCT, which did not appear to be an issue in this study. However, it was evident that there was a lack of collaboration and consultation between hospitals and ID services. The importance of networking and developing formal links with specific hospital departments was identified as important in addressing this situation.

7.2 Communicating Death Related Bad News in Intellectual Disability Services

A lack of discourse, regarding the topic of death and dying in general, and end-of-life care in particular, was identified in this study. A culture of silence was discernible from an organisational perspective and was also evident in ID staff and families supporting the person at the bedside. This impacted on the general discourse in relation to death and dying with organisations and impacted on the *"breaking of bad news".*

7.2.1 Conversation about death and dying

All ID staff, families, and decedents in this study were Irish nationals and wider Irish societal attitudes to death and dying and issues in relation to end-of-life care may have impacted on communicating death related bad news. Irish people are not comfortable discussing the issue of death and dying and are not well informed as to what happens when a person is dying according to McCarthy et al. (2010). McCarthy's account of Irish cultural attitudes to death and dying is supported by the findings of Weafer et al. (2014) who explored Irish attitudes to death, dying and bereavement, from 2004 to 2014. These authors found that, in 2014, only 35% of the Irish population believed there was sufficient discussion of issues relating to death and dying in Irish society. In a previous study, undertaken in 2004, 30% of the population held this belief, indicating that little has changed in the intervening decade. This suggests an entrenched reluctance on behalf of Irish people to engage in conversations relating to death and dying and end-of-life issues in general. Reflective of this cultural perspective, families and ID staff to a certain extent, stated that they too avoided the topic of death and dying and end-of-life issues in general. This avoidance of the topic, by families in particular, was not just specific to the person with the ID. Families also indicated that they did not discuss the fact that their sibling was dying amongst themselves. ID staff, providing direct care to the individuals involved, also indicated that they sought to avoid discussing the issue of death and dying and, in a minority of cases, felt that the task of breaking bad news should be left to doctors or to CNMs.

The families in this study also indicated that, in some cases, the decedents themselves did not want to engage in conversations about their end-of-life care. In these cases, families and staff used their knowledge of, and past experiences with, these individuals when making the decision not to inform them they were dying. Bekkema et al. (2014) reason that it is important to link past experiences with an individual to their current situation when trying to ascertain the will and preferences of the person involved, an approach consistently used by families and ID staff in this study. ID staff too indicated that service users rarely sought out opportunities to talk about end-of-life issues, even in the event of the death of another service user. However, these staff also noted that they were not encouraged to do so either.

That people with an ID might exhibit the same reluctance to engage in conversations on end-of-life care as people in the neurotypical population has been identified by Tuffrey-Wijne et al. (2013). When given the opportunity to have such discussions, people with an ID presented mixed perspectives on the topic. Some indicated they did not want to talk about death and dying and others wished to actively engage in such conversations (Tuffrey-Wijne et al. 2013). The findings of this study suggest that people with an ID and members of their circles of support may be equally uncomfortable when it comes to discussing issues relating to death, dying and end-of life care, reflective of Irish cultural attitudes in general.

This culture of silence was also evident at an organisational level as no reference to the provision of end-of-life care was identified in the mission statements or service information available from organisations. There was also a distinctive lack of signposting of the end-of-life care supports available for service users. That a culture of silence existed at organisational level might not be unusual, since, as suggested by Todd (2007), the topic of end-of-life care has become taboo in ID organisations. These organisations, having rejected the *"sick role"* previously associated with disability, turned to a social model of care ethos. This study has identified that while this largely continues to be the case, a growing awareness of the need to address the issue of death and dying is apparent in this study. When faced with an ageing population, with increased health needs and future end-of-life care requirements, organisations have adapted and continue to adapt to meet the needs of service users at end of life. Changing the culture of a service can be difficult, as evidenced in this study. However, managers indicated that, despite these difficulties, changes were made to services in order to ensure that the end-of-life care needs of individuals could be met in conjunction with the social, emotional and psychological support they required.

The lack of discourse in relation to end-of-life care and advance care planning was also evident in that none of the organisations had a policy in place to address end-of-life care needs or advance care planning, which would appear to be typical of many ID organisations (D'Haene et al, 2010). However, again reflective of a changing approach within the organisations in this study, policies relating to providing end of life care were being developed. These were driven, in the main, by service managers who were instrumental in effecting change in relation to end-of-life care across these organisations, both at service and policy levels. Many of these service managers, had a particular interest in end-of-life care, and had undertaken educational courses to enhance their own knowledge.

7.2.2. Breaking bad news

The culture of silence exhibited at organisational level, was also evident in families and staff supporting people with an ID and impacted on how the issue of breaking bad news was approached. That both families and staff supporting the individuals in this study were reluctant to tell them that they were dying is reflected in the findings of other studies, both nationally and internationally, (Wagemans et al, 2010; Tuffrey-Wijne, 2013). In this study, only one of the nine decedents were aware that they were dying. All families, bar one, were happy with their decisions not to inform their loved one. ID staff, with the exception of one individual, indicated that people with an ID should be informed they were at end of life. However, reflective of the approach to families, they avoided discussing the issue, a trend identified in national and international research (Bekkema et al. 2014 a; Wagemans et al. 2010), and in a minority of cases, felt that the task of breaking bad news should be left to doctors or clinical nurse managers.

Both families and staff proffered a number of reasons why they chose not to engage the person in conversation about end of life. In the main, families and staff stated that the person lacked the capacity to understand, an issue which has been cited as a reason for not engaging in conversations about end-of-life care in a number of studies (Wagemans et al, 2010; McCarron et al. 2018). Both families and ID staff made this assertion, based on the level of ID of the person and other co-morbid health conditions such as dementia. While this contention might be considered reasonable, the NCP (2017), clearly states that where the decision making capacity of an individual is unclear, a capacity assessment must be undertaken. It cannot be assumed that the person lacks capacity based on the diagnosis of a disability or other medical condition, as was the case in this study.

The issue of communication was also raised by families and staff in relation to informing the person of their diagnosis. That families and staff lack the skills to engage in conversations about death and dying and end of life, is an issue that has been raised across multiple jurisdictions (Mortan-Nance and Schafer,2012; Tuffrey-Wijne, 2013).

However, in this study, neither families nor staff expressed any concerns about their ability to undertake these conversations, although all indicated they avoided such conversations. Their lack of concern may be explained by the fact, that from the point where it was clear the person was at end of life, there appeared to be an unspoken consensus between families and ID staff that the person would not be informed.

In the main, families and staff were worried about the expressive communication ability of these individuals. These concerns may be reflected in the fact that the majority of those in this study had a moderate to severe level of ID and were non-verbal. Families, in particular, were concerned that the person might not be able to express their fears and let their family members know how they were feeling about their situation if they were informed, they were at end of life. That families and ID staff expressed these concerns is not unique. Bekkema et al. (2014) also found that it is more difficult for those supporting people with a severe to profound ID to identify their information requirements at end of life, when compared to those with a mild to moderate ID.

The timing of conversations was also an issue in this study. Staff, in a number of cases, stated that people were too tired or ill to be able to engage in end-of life conversations at the time they were occurring. A reticence to engage in conversations about end of life within the organisations involved and the lack of advance care planning meant that, often times, these conversations did not occur when people had the cognitive and physical capacity to engage in them. In addition, it was also evident, in some cases, that both families and staff did not recognise that a person was beginning their end-of-life journey.

In some instances, the individuals in this study, had previously been extremely unwell and then rallied. Families and staff became accustomed to these individuals *"bouncing back"*, and in many cases, did not realise this was not going to happen again. In these situations, conversations about end-of-life care did not commence until two to three days before the person died. In other cases, decedents had become acutely unwell before any serious consideration had been given to their end- of-life care. The lack of advance care planning processes within the three organisations appeared to exacerbate this situation.

Another factor, and one specific to staff, is that staff took their cue from families when it came to breaking bad news. If the family did not want to disclose that the person was dying, then the staff did not do so either.

That ID staff accepted and adhered to the decisions made by families is also reflected in the findings of other studies, where it was identified that care staff, in particular, felt that the wishes of families, should take precedence where the person lacked capacity (Wagemans et al. 2013 a; Bekkema et al 2014).

Within an Irish context, the NCP (2017) and ADM (2015) are changing the legal landscape, from a Wardship approach, as discussed in Chapter Two. However, that staff took their lead from families may be linked to this wardship based approach, which has been in existence for decades. Staff were used to consulting and making decisions with families and, in many situations, families were the final arbitrators with respect to decisions about their loved one. In addition, person centred planning processes calls for the inclusion of family members, therefore, ID staff were used to regularly consulting with and sometimes acquiescing to the decisions of family members. That the decisions of family members carried great weight was evident throughout the cases in this study and particularly so, in one case where the wishes of the decedent's mother, continued to be respected, even after her death, and despite her son's changing medical circumstances.

Both family members and ID staff, also indicated that they wanted to protect the people in this study from the harsh reality that they were going to die. Those who felt the need to protect these individuals expressed a strong belief that people should be spared, what they perceived as, the pain and distress associated with this disclosure. This perspective was also referred to by managers, who reported that staff expressed deep reservations about instigating advance care planning because of a fear that the individual involved would be overwhelmed. Both families and staff spoke with great emotion of their need to protect these individuals. The issue of emotional ties between those involved in circles of support has been identified in other studies, which also found that emotional ties can culminate in a drive to protect the person involved (McCarron et al 2018; Bekkema et al, 2014; Todd et al. 2013).

The need to protect the individual involved may also be linked to the fact that eight of the nine decedents in this study were siblings of the person involved. The fact that siblings play such a fundamental role in the care of their brothers and sisters is not unusual as according to Buys (2008) this generation of people with an ID are amongst the first to outlive their parents. That siblings are playing more prominent roles within an Irish context, was also identified by Leane et al. (2016, p.70), who found that siblings who took on the *"most involved sibling role"* were those with an emotional attachment to their brother or sister and felt they understood them best. In this study, all siblings interviewed referred to their emotional bond with their brother or sister.

This attachment was expressed in their stories of their lives with their siblings and the loss they experienced when their sibling died. In this study, this emotional attachment, may explain the needs of siblings to protect their brother or sister and the extent to which they were determined to be there to support them at end of life.

While families and staff were reluctant to talk about aspects of death and dying and end-of-life care, this reticence did not extend to planning an individual's funeral. All organisations in this study had a clear process and mechanism for recording and enacting funeral arrangements, in an end-of-life form. None of the ID staff interviewed indicated any disquiet at broaching the subject of funeral arrangements with family members, a finding echoed by McCarron et al. (2018) who also found that Irish ID services had policies in relation to documenting funeral arrangements in advance.

Family members, in turn, indicated that they had discussions with ID staff about their loved one's funeral arrangements, and many were grateful that the staff took care of these arrangements. That people find it easier to have discussions about what happened after death as opposed to before it may, again, be linked to wider Irish societal attitudes to death and dying. Weafer (2014) found that 75% of Irish people had discussed whether they wanted to be buried or cremated, whereas only 35% have identified their preferences for care at end of life. These statistics reflect the fact that both staff and families, as identified in this study, are more comfortable discussing what happens after a person dies than their end-of-life care prior to death, a finding echoed in other jurisdictions (Tuffrey-Wijne & Rose, 2017).

To conclude, it is evident from the findings of this study that a culture of silence exists in ID organisations with respect to the provision of end-of-life care and advance care planning. People with an ID are not informed of their diagnosis or included in decisions in relation to their end-of-life care and the reasons for this are complex. While issues relating to capacity and communication are important; to assume that people with an ID are not included solely based on capacity and communication issues alone, would be an over simplistic representation of this issue.

When interviewed, while initially families and staff did discuss these issues, they spent the majority of the interview describing factors which reflect the complex interweave of relationships between the decedent, their circle of support, and the environment in which they were cared for. These factors include a reluctance amongst Irish people, from a societal perspective to engage in conversations about death and dying and a culture of silence within ID organisations in relation to end-of-life care.

The availability of end-of-life care supports in ID services were not well sign posted and there are few policies and processes in place to guide the development of services, or, to support staff who provide this form of care. This culture of silence can, to some extent, be explained by a strong social model of care ethos within organisations, and the rejection of the *"sick role"* historically associated with disability.

This reluctance to engage in end-of-life conversations was also evident in the perspectives of families and staff and the person with the ID themselves. A lack of advance care planning processes in organisations also impacted on conversations taking place in a timely manner. It was also evident that ID staff had developed working relationships with families over decades, and where decisions had to be made, ID staff were often led by the decisions of the family involved. Other issues, common to both families and staff, were also identified. A desire to avoid the topic of end of life in general, wanting to protect the individual, and respecting that an individual may not want to be told were seen to influence whether people were informed of their diagnosis or not. Overall, the avoidance of the topic of death and dying by staff and families meant that the voice of the decedents in relation to their end-of-life care were lost, an issue which is explored in the following section.

7.3 End-of-Life Decision Making Practices

The issue of end-of-life decision making, and advance care planning is a central theme in this thesis. The manner in which decisions were made, and the form these decisions took, were impacted by a number of factors. These included the extent to which people with an ID were included in decision making, the role of circles of support, and the timing of decisions.

7.3.1 Inclusion of people with an intellectual disability in decision making

This study has identified that, irrespective of the level of ability of the individual involved, or the extent to which the person had insight into or were aware that they were dying, they were not included in decisions about their end-of-life care. This is not unique to the Irish ID population as studies from the Netherlands, Switzerland, and Australia (Bekkema et al. 2014; McKenzie et al. 2017; Wicki & Hättick. 2017) have also identified this. That people with an ID were not included in decision making is unsurprising, within the context of this study, given that only one of the nine decedents were told they were dying, which has often times been identified to be the case with this population (Tuffrey-Wijne et al.2007; 2010)

However, this study identifies an interesting anomaly in that while people with ID were excluded from making end-of-life care decisions, there was abundant evidence of proactive approaches to include them in decision making in other aspects of their lives. Decedents in this study, made important life decisions such as where they would live, when they would retire, as well as financial decisions.

It was also identified that, irrespective of whether those in an individual circle of support agreed with their decision or not, the decision of the individual was respected. This is in keeping with the requirements of the NCP (2017) which requires that a person's decision, where the person has capacity, be respected, even if considered an unwise or unreasonable decision by others.

In addition, and in keeping with the NCP (2017), the study's findings suggest that staff in the ID services subscribed to a relational perception of autonomy, as discussed in Chapter Two of this thesis, and sought to enhance the decision making capacity of people with an ID, through the use of independent advocacy services. These findings differ from O'Donovan et al. (2016) who found that people with an ID in Ireland are not involved in major life decisions and those in residential services are least likely to make decisions. That the individuals in this study were supported to engage in decisions about their day to day lives may be reflected in the fact that the three organisations had a strong focus on a social model of care and delivering person centred care. As per a person centred planning approach, regular meetings were held with the decedents and their families to identify their will and preferences and it was clear, in the files of the individuals involved, that staff sought to ensure that the voice of the person was heard and acted upon in relation to day to day issues.

However, this proactive approach to decision making changed when the person was diagnosed with a significant health issue and the decedents were excluded from the decision making process. Discussions did not take place between members of individual circles of supports to determine if the person would want to be, or should be, involved in decisions about their end-of-life care. As previously stated, there appears to be an unspoken consensus that the person would not be informed. This lack of discussion may be reflective of Irish societal attitudes towards avoiding discussing issues in relation to death and dying, and breaking bad news, as identified in this study, and studies of the Irish neurotypical population (McCarthy et al. 2010). Irrespective of the reason why the person was excluded, it impacted on how decisions were made on their behalf and the form these decisions took.

7.3.2 The role of circles of support in decision making

As evidenced in the cases in this study, a wide variety of people were involved in decision making at end-of-life and the importance of the relationship between these individuals and the person who was dying became evident. While the decedents in this study were not actively included in decision making, a relational approach to autonomy was evident as both families and staff drew on their past experiences of the individuals involved, their likes and dislikes, or things that caused them distress, to inform the decision making process.

Reflective of the respectful relationships between the decedents in this study, their families and ID staff stated they could not speculate as to whether they had fulfilled the wishes of their loved one or not. In some cases, family members openly discussed that they were not sure what their loved one wanted at end of life. A member of staff felt that it would be presumptuous of staff to assume the wishes of an individual had been fulfilled, in the absence of discussing this with them.

In the majority of cases, decisions made on behalf of these individuals were made by family members and medical professionals, be they consultants in acute hospitals or community based GPs. In some cases, the perspectives of family members carried great weight and determined the decisions made, in line with other studies (Wageman et a. 2013 a; Bekkema et al. 2014). Some families were proactive in instigating the decisions making process. In many cases, they were motivated by an effort to ensure their loved one did not experience pain or distress or experience burdensome treatments. That families prioritised these issues, are reflective of the perspectives of families across jurisdictions (Bekkema et al. 2014a; Wagemans et al. 2010). However, in other cases, families were not active participants in the decision making process. Instead they appeared to place their trust in medical professionals and were happy to be *"kept informed"* of decisions taken, an issue which has not been identified in other studies.

It could be surmised that in cases where families indicated that they did not fully understand the issues facing their loved ones, they took a step back and left the decision making to professionals. It could also be a factor that since many of the decedents in this study had been in residential care for decades, families might have been socialised into leaving day to day decisions to the ID staff and other health professionals supporting them. Given that families were used to approaching decision making on a day by day basis, it is unsurprising that they adopted the same approach to end-of-life decision making.

Families indicated that they did not plan ahead in general and dealt with situations as they arose. This approach to decision making is reflected in the fact that, in some instances, in this study, people were admitted to residential care having been hospitalised when their health deteriorated or that of their parents. This ambivalent approach to decision making is also reflected in their decision making approach to end-of-life care, where reactive as opposed to proactive approaches were evident. This finding suggests that families may be reluctant to engage in all forms of future planning, not just advance care planning, a finding reflected by Leane et al. (2016). Finally, Weafer et al. (2014) found that only 35% of Irish people had discussed their preferences for end-of-life care with another individual. In light of this, it stands to reason that Irish people may be equally reticent in planning the end-of-life care of another person, if they are disinclined to plan their own.

ID staff were least likely to be involved in advance care planning. In some instances, ID staff indicated that they felt excluded from decisions made. That ID staff felt marginalised in these situations may be linked to the fact that medical professionals predominately dealt with the families involved. However, ID staff also indicated that they prefer to abdicate the responsibility for engaging in these conversations to medical professionals or the CNM. That this is the case has also been referred to by Tuffrey-Wijne and Rose, (2017), who reference the importance of the role of the service managers in encouraging staff to engage in these conversations by leading by example.

The majority of decisions in this study were made by siblings, which is an issue that has not been identified in other studies relating to decision making at end-of-life. The growing number of siblings taking on support and decision making roles has been identified in an Irish context (Leane at al., 2016., Lafferty et al., 2016). According to Coyle et al, (2015) this occurs as parents age and become frailer and cannot fulfil the role of carer. Family members in this study were influenced by those who had previously supported their sibling. In many instances, it was clear that siblings were not making decisions from their own perspective, or that of their sibling, but became conduits for the decisions made by their parents.

Family members also spoke of the fact that the decisions they made were influenced by how their parents had approached care giving and, in many cases, family members had made promises to their parents in relation to the care of their sibling, which they felt honour bound to fulfil. In the main, these promises related to protecting their sibling, and may have influenced their decisions to protect their sibling from what they perceived as difficult decisions in relation to their own end-of life care. However, no reference was made by family members in this study to concrete discussions taking place about what would happen to their sibling in the future, in general, or in relation to end-of-life care specifically, indicating again, that families do not engage in decision making in advance.

7.3.3 End-of-life decisions made

Decisions made in this study, seemed to be heavily influenced by the timing of when they were made. As identified in section 6.2.2. of this thesis, decisions in relation to end of life care, were in the main, made a number of days before the person died. The lack of an advance care policy in place to guide and support staff and families in undertaking advance care planning, impacted on the decisions made. This approach to facilitating end-of-life decisions, contrasts with the approach taken to person centred planning, where policies explaining the process and forms for documenting decisions, were readily available. However, despite the fact that the standards for residential services state that end-of-life care should fall under the remit of the person centred planning process within organisations, (HIQA, 2013) this did not occur.

Therefore, opportunities to engage in advance care planning, at a time when the person involved would have decision making capacity or could be supported to make these decisions in conjunction with their circle of support, were lost. Additionally, a lack of advance care policies to guide and support staff in relation to advance care planning, also negatively impacted on the timing of end-of-life discussions.

This meant that both families and ID staff engaged in reactive as opposed to proactive approaches to decisions making, as they responded to the changing care needs of the individual involved. This reactive approach to decision making is reflected in the fact that the vast majority of decisions which were documented, related to medical issues such as implementing DNR/NFR, the withdrawal of treatment or whether to transfer the person to a hospital setting. Decisions in relation to symptom management, such as the management of pain and oral excretions were also routinely documented. Given that, in the majority of cases, decisions began to be made close to the person's deaths, it is unsurprising that discussion and decisions were focused on comfort care. The fact that medical related decisions predominate advance care planning in the ID populations has been identified across multiple jurisdictions (Wagemans et al.2010., Bekkema et al. 2014a; Witchki & Hallich 2017., Voss et al. 2019).

While both families and staff alluded to the fact that end-of-life decisions relating to the social, psychological and emotional care of these individuals were discussed, these discussions were not documented. In addition, there was no mention of what was to happen to their belongings, despite the fact that, in some cases, it was evident that people had bought or been given things that were of importance to them. That decisions beyond the medical care of individuals are not taken, or at least not documented was also reported by Voss et al. (2019).

Overall, it has been difficult to ascertain what decisions were made in relation to end-of-life care as most of the information documented is related to medical decisions only. Where references were made to a discussion held and decisions made, little concrete information that one would ordinarily expect to be provided was available. Who was involved in discussions, what was the motivation for each decision, how was the decision made, and the outcome of these discussions were not always clearly documented. In some instances, the fact that a decision was made at all, was only established through the course of the interviews in this study.

To conclude, people with an ID were not included in end-of-life decision making. In the main, these decisions were made by family members and medical professionals. The majority of decisions made related to DNR/NFRs and the withdrawal of treatment.

While families and staff did indicate that broader discussions in relation to the end of life care of individuals did take place, limited documentation of these decisions or their outcome was identified. In many cases, the only reference to decision making processes was a reference to the fact that a discussion had taken place. Therefore, the decision making processes involved in end-of-life care in this study, remain elusive, as has been found in studies in other jurisdictions (Voss et al. 2019).

7.4 Conclusion

At the outset of this study, it was stated that, despite an increased focus on research in end-of-life care and advance care planning, people with an ID remained a largely invisible population, with limited evidence of how people are supported at end of life and by whom. In addition, there was limited evidence of decision making practices, as they related to end-of-life care. This study has helped to address this lacuna, by identifying a variety of complex issues, which not only impact people with an ID themselves, but all impact the on the family's staff and services who support them on their end-of-life journey.

The findings of this study have identified a number of key factors which impact end-of-life care and decision making practices in specialist ID residential services. From an organisational perspective it is evident that organisations supporting people with an ID were impacted by the emergence of an ageing population within specialist services leading to an increased demand for end-of-life care. In addition, many of these services, were community based services, providing end-of-life care, along with a diverse range of other supports and services, to people with varying levels of needs and abilities. Given the ongoing policy of decongregation in Ireland, it is likely that more and more community based services will be called on to provide end-of-life care into the future.

It is also evident that people with an ID are supported by a variety of individuals including families and health care professionals within these specialist services and across community based and acute hospital and hospice services. All individuals, across these services were committed to providing support at end-of-life, irrespective of the location in which the decedents in this study died. Most particularly, families and ID staff who, in many instances, had known these decedents for decades and had built up a bedrock of knowledge in relation to these individuals, were determined to be there to support those involved.

Those involved in the circle of support around each individual collectively used their shared knowledge of these individuals to promote their autonomy and advocate on their behalf. Service managers also showed commitment at an organisational level by ensuring the development of, or changing the culture within, pre-existing services to support people to age and die in place.

Where this was not possible, service managers were instrumental in ensuring that staff from ID services were available when required to support people with an ID at end of life and their families, in external services. ID staff also showed ongoing commitment by supporting these individuals in external services, in their own personal time. However, ID staff did not feel that their role in providing end-of-life care was fully understood at senior management level. Staff felt this needed to change as they recognised that services needed to continue to adapt to provide end-of-life care into the future and to make end-of-life care visible within the organisations involved.

Despite the level of sustained commitment to providing end-of-life care, all those involved, at both individual and organisational levels encountered a variety of issues which negatively impacted on end-of-life care and decision making in specialist ID residential services. Firstly, within ID services, policies and processes relating to end-of life care did not exist, leading to a culture of silence within organisations relating to death, dying and end-of-life care. Despite this lack of guidance and organisational polices, organisations did develop and adapt services to meet the needs of an aging population. Service managers in particular, were instrumental in adapting services and pushing for the development of policies to support end-of life care.

Another issue which arose, was the issue of preparedness for providing end-of-life care. In many instances, both family members and ID staff did not appear to recognise that the person was at end of life. This was in some instances attributable to the fact that many of the decedents in this study had been seriously ill before and *"bounced back"* and in some cases, the families and staff involved did not recognise that this was not going to happen again, until close to the death of the individuals involved.

When called upon to provide end-of-life care, healthcare professionals across services appeared to encounter issues when supporting people with an ID. Staff within specialist ID services, in some situations, lacked the skills in relation to providing end-of life care and heavily relied on the support of the CPCT. Conversely, staff in the acute hospital setting did not appear to have all the required skills to support people with an ID and were heavily reliant on the input of staff from specialist ID services and family members.

Within ID services, issues arose with providing end-of-life care especially in community based services. Some services, did not have the capacity to provide end-of-life care leading to people having to be transferred within the organisations involved, suggesting that inequity may exist in the provision of end-of-life care within organisations. Despite these issues, service managers and ID staff strove to provide appropriate end-of-life care, by developing or adapting services, and linking with external services, most specifically GPs and CPCT.

Where appropriate supports were provided in ID specialist residential services, those availing of these services could be provided with appropriate end-of-life care. This was true, even for small community based services, where ID staff indicated they encountered the greatest number of challenges, when providing end-of-life care. Where the end-of-life care of an individual was beyond the scope of specialist ID residential services, as previously mentioned, those within their circle of support continued to support then in external services.

Issues in relation to collaboration and consultation between services were also identified. While communication between community services and specialist ID services was seen to be good, issues were identified in terms of communication between ID services and acute hospital settings. In a minority of cases, service managers within ID services had established links into the hospital setting, which positively improved their interactions with each other, thus highlighting the importance of networking, developing formal links and integrating health and social care services.

All of those involved identified issues in communicating death related bad news leading, as previously mentioned, to a culture of silence both at an organisational and individual level. At an organisational level, there was a marked lack of policies and processes in relation to end-of-life care which starkly contrasted with how other aspects of service delivery, such as person centred planning processes were dealt with.

At an individual level, only one of decedents in this study was informed that they were dying, irrespective of their level of ID or decision making capacity. In some instances, issues intrinsic to the person such as capacity, communication barriers and a preference not to be informed were identified as impacting on disclosure and discussions around end of life. In other instances, factors external to the individuals such as a need to protect the individual involved, and ID staff and families wanting to avoid conversations about end-of life decisions were seen to impact. Irish cultural attitudes to end-of life issues were also felt to impact on conversations about death, dying and end-of-life care suggesting Irish people with and without an ID, may be equally uncomfortable, when discussing these issues.

With respect to decision making at end of life, this study has identified that while people with an ID were proactively supported to make a wide range of decisions, this supportive stance did not extend to end-of-life decisions. People with an ID were not involved in end-of-life decisions although a relational approach to autonomy was evident as both families and ID staff, independently and collectively, drew on their knowledge of the individuals, to make, to the best of their ability, the right decision for the person, at that time.

The timing of end-of-life decisions appeared to have a particular impact on decisions made. Firstly, the absence of policies and supports within specialist ID residential services for engaging in advance care planning, meant that these decisions were made when the decedents involved no longer had the cognitive and physical ability to engage in these decisions. Secondly, given that these decisions were made close to the deaths of those involved, in the main, they related to medical decisions and decisions in relation comfort care. These decisions were mainly made by family members, in consultation with medical professionals, with little input from ID staff in specialist services. In the main, little documentation of decisions other than DNR/NFR, withdrawal of treatment or decisions in relation to transferring people to acute hospital was found. In addition, those involved in decision making in this study, were siblings of the decedents in this study, who had taken over the caring role from their parents. These individuals were influenced by the manner in which their parents had cared for their brother and sister and the decisions they had previously made and were very focused on protecting their siblings, sometimes, as a result of promises they had made to their parents to always ensure that their brother or sister was protected.

ID staff within specialist residential services recognised the importance of end-of-life decision making and were sometimes involved in these decisions, mainly at the level of service manager. However, ID staff generally appeared reluctant to initiate discussions with people with an ID and their families in relation to end-of-life care. The importance of service managers in promoting advance care planning and supporting staff to engage in conversations about death, dying and end-of-life care was evident.

It is clear that specialist ID residential services are able to provide end-of-life care for people with an ID where an appropriate skill mix and the required resources are provided. There is evidence of a commitment to provide end-of life care at a variety of levels, most specifically, at the level of individuals within specific circles of support. At a service level, services have either been developed or adapted to meet the changing needs of an emerging aging population in the absence of robust organisational and national policies. Service managers in particular, were seen to be instrumental in adapting services to meet the end-of-life needs of individual service users and in advocating for the development of appropriate polices to support end-of-life care with specialist organisations. However, despite this commitment, issues have arisen which must be addressed. These issues have implications in terms of clinical practice, education and research and recommendations will now be presented, to address these issues.

Whilst this study has focused specifically on end-of-life care supports and decision making practices in specialist ID residential services, the findings of this study are also reflected in the

findings of end-of-life care research undertaken within the neurotypical population, both nationally and internationally.

7.4.1 Implications within the overall context of end-of life care

Firstly, as identified in this study, health and social care services are having to adjust to the demands of an ageing ID population, with an increased number of co-morbid health conditions and a prolonged period of dying. This trend is also reflected, within the neurotypical population, in international and national literature. The National Institute of Health and the WHO in 2010, stated that 8% or 254 million of the world's population were over the age of 65 (Richard & Beard, 2011). The WHO predicted that this would rise to 16 % by 2050, with over 1.5 billion people in the world, over the age of 65. This trend has also been identified in an Irish context, with the number of people in Ireland over the age of 65, rising by 102, 174 or 19.1% between 2011 and 2016 according the Central Statistics Office.

Both nationally and, internationally an increase in comorbid health conditions has also been identified in ageing populations. Afshar et al. (2015) compared multimorbidity across 28 low and middle income countries, drawing on data from the WHO World Health Survey. This study identified that multi-morbidity in aging adults is a global phenomenon. In an Irish context, Turner et al. (2018, p.13) have identified an increase in comorbid health conditions in the neurotypical population between 2009 and 2018, with an increase in the prevalence of conditions, such as:

> *"falls (20% to 52%), arthritis (26% to 39%), osteoporosis (9% to 17%), cataracts (9% to 14%), hypertension (35% to 38%), diabetes (8% to 11%), wrist fractures (12% to 14%), heart attacks (4% to 6%), transient ischaemic attacks (2% to 4%), lung disease (4% to 5%) and strokes (1% to 2%)".*

Within the context of the provision of palliative care, the estimated number of people in need of palliative care at end of life is 20.4 million, according to the World Palliative Care Alliance (WPCA) (2014). Over 94% of those requiring palliative care are adults, of whom 69% are over 60 years of age. The WPCA has also stated that there are significant numbers of people who will not be able to access palliative care, as only a minority of countries have established equitable palliative care programmes.

Reflective of international findings, the Irish Hospice Foundation (IHF, 2013) in its report on the strategic importance of palliative care within the Irish health service identified that, as is the case in the ID population, the demand for palliative care nationally is growing as people are living longer with life-limiting conditions.

Despite the fact that policy makers across jurisdictions have emphasised the importance of providing end-of-life care for those who require, it is evident in national and international empirical literature, that there are issues in accessing these services, in a timely manner (Janah et al.2019., Craigs et al, 2018).In this study, it was found that while people with an ID had access to palliative care services, often times this occurred, very late in the trajectory of their illness. In the majority of cases, individuals began availing of palliative care services in the final few days of their lives. This finding has also been identified in other studies relating to the ID population (McCarron et al. 2018) and in studies undertaken in the neurotypical population (Janah et al.2019., Craigs et al, 2018., Rosenwax, 2016). In a study of French cancer patients, 57% (n= 40,941) had access to palliative care services. However, reflective of findings in the ID population, in the majority of cases, these services were accessed in the final month of the person's life. Late referral to palliative care services has also been identified as an issue in the neurotypical population in studies undertaken in the United States, (Hui et al, 2012), the United Kingdom (Craigs et al, 2018) and Australia (Rosenwax, 2016). Therefore, it is evident that despite the fact that policy makers are drawing attention to the need for palliative care services, accessing palliative care services in a timely manner, continues to be an issue for all, across a number of jurisdictions.

It was also evident in this study, that people with an ID and the families and staff supporting them were reluctant to have conversations about death and dying in general or to discuss their own specific wishes in relation to their own end-of-life care. This finding is reflected in international findings according to the WPCA (2014) who contend that individuals, in many countries fear and avoid discussing issues relating to death and dying. Within an Irish context, both McCarthy et al. (2010) and Weafer et al. (2014) have also identified that Irish people are not comfortable talking about death and dying and do not plan ahead when it came to their own end-of -life care.

This study also found that those supporting people with an ID at end of life do not engage in advance care planning. That this is the case, has also been identified in other studies specific to people with an ID (Wagemans et al. 2010., Witchki & Hallich 2017). This has also been identified as an issue in the neurotypical population (Cornally et al. 2015). One of the biggest challenges identified in the advance care planning literature is the issue of capacity (Cornally, 2015). Within an Irish context, Cornally et al. (2015) have identified that support staff encountered issues in identifying if an individual had the capacity to engage in advance care planning. This study found that staff needed ongoing support and education when implementing advance care planning.

This study also established that the culture within organisations are not always conducive to the implementation of advance care planning. This issue has also been identified in other forms of residential services, such as care of the elderly settings. McGlade (2018) explored health professionals' knowledge of advance care planning in Ireland, Canada and the United Kingdom, and found that advance care planning was not happening in care of the elderly settings and that decisions in relation to resuscitation were left until the death of the person was imminent. That advance care planning is not being implemented systematically in residential care services has been identified across a number of jurisdictions including Norway (Bollig et al. 2015), Australia (Silvester et al. 2013) and the United Kingdom (Beck, 2017).

With respect to decision making in end-of-life care for people with an ID, this study identified that people with an ID were not included in end-of-life decision making. In the main, these decisions were made by family members and medical professionals. The need for legislative changes to protect the right of autonomy and the right of individuals to make decisions about their own health care has been identified across many jurisdictions. A number of countries including England, Scotland, Germany, Canada and Australia have enacted legislation which takes a functional approach to assessing capacity. This is also the case in an Irish context. In light of the changes that will be required as a result of the enactment of the ADM (2015), the role of families and staff and how decisions are documented will have to change not just for people with an ID and their circles of support but also in the neurotypical population.

To conclude, there is much commonality in terms of the issues faced by people with an ID and those from the neurotypical population at end of life.

While it is important to acknowledge that people with an ID may require specialist supports at end of life, such as access to appropriate communication supports , many of the issues impacting people with an ID also impact those in the neurotypical population, across jurisdictions.

It is evident from the national and international policies identified here, that all jurisdictions are facing an increasing older population, with multimorbid conditions, who will need to access the palliative care supports. However, empirical research has identified ongoing issues in the provision of end-of life care. Firstly, may people who require end-of life care do not have access to it, or cannot access support services in a timely manner.

Secondly, it is also evident that advance care planning is not implemented in a systematic manner, in residential care services. This means that people are not being included in decisions regarding their end-of-life care, impacting on their right to autonomy. In addition, decisions are being made, close to the death of the individuals at a time when families are under duress and therefore decisions made are mainly confined to issues relating to DNR and hospital transfer.

It is evident that there is a reluctance, to discuss the issue of death and dying both nationally and internationally, which inhibits open and forthright communication about many issues relating to end-of- life care. More needs to be done to promote effective communication and collaboration between the person at end of life and those who are supporting them, both to address the needs of those with an ID and those in the neurotypical population.

7.4.2 Implications for clinical practice

From a practice perspective, it is evident that those supporting people with an ID are committed to providing end-of-life care. However, despite this commitment, issues have arisen which must be addressed from a clinical perspective. Firstly, the reported disconnect between senior management and staff providing end-of-life care must be addressed. It is important that a top-down, bottom-up approach is taken to providing end-of-life care. Effective communication between all those involved, from front-line staff to service managers to senior management is a prerequisite to ensuring effective policies and efficient services are available to support people at end of life

Specialist ID organisations must develop or adopt end-of-life policies to support the development of end-of-life services within these organisations.

This must be done to ensure that services are developed which can offer supports to the burgeoning ID population who will require end-of-life care into the future. Organisations must also seek to ensure that the issue of the end-of-life care of people with an ID, is discussed at a national level, through groups such as Inclusion Ireland who engage with government officials, in order to promote the rights of people with ID. Most specifically, given the current national decongregation policy (HSE,2011) specific attention must be placed on supporting community based services to provide end-of-life care, in order to ensure equity of access to end-of-life care supports in specialist ID residential services.

The culture of silence evident within specialist ID residential services must be addressed to ensure open communication takes place in relation to death, dying and end-of-life. It is paramount that these conversations take place in a timely manner to ensure people with an ID are supported to actively participate. It is also imperative that the knowledge and support of those within their circles of support is harnessed to ensure their end-of life wishes are identified and adhered to.

Preparedness to provide end-of-life care is also an issue which must be addressed. ID staff in specialist residential services must be supported to develop their knowledge and skills in relation to end-of life care. Health professionals in acute hospital settings also need to be supported to enhance their knowledge and skills in relation to ID. As evidenced in this study, these settings are heavily reliant on the input of family members and staff from specialist ID services when caring for people with an ID. This issue will need to be addressed by closer networking between specialist ID and acute hospital settings, to develop more integrated services. The development of specialist liaison ID nursing roles within acute hospital settings must also be undertaken to ensure that people with an ID are appropriately supported within hospital settings, without undue pressure being placed on family members or specialist ID services.

All of the organisations involved in this study, had processes developed to promote engagement in person centred planning and to enable people with an ID to make autonomous life decisions. For those, whose cognitive ability meant that they required the support of those who knew them well, these person centred planning approaches provided opportunities for those within their circles of support to meet and harness their collective knowledge of the individual involved, reflective of a relational approach to autonomy. However, person centred planning processes did not extend to end-of-life care.

This must change if conversations in relation to end-of-life care, are to be undertaken in a manner which ensures the will and preferences of the person with the ID and the collective knowledge of circles of support are captured and used to ensure holistic end-of-life care is provided to people with an ID, within specialist ID residential services.

Staff within ID organisations must be supported to initiate discussions relating to end-of-life care with both the person with an ID and their families, in a timely manner.

The integration of advance care planning into current person centred planning processes should foster the development of a culture within services where issues in relation to death, dying and end-of-life care are discussed in a pragmatic manner. Given the fact that this study has identified the significant role played by siblings, person centred planning processes could also be used to encourage families to plan ahead and identify who would be involved in supporting the person in the future and ensuring these individuals are involved in person centred planning processes as early as possible.

How issues relating to promotion of communication and capacity are addressed, and how decisions relating to end-of-life care are made, needs to be made explicit to ensure the autonomy of people with an ID is protected and promoted when making end-of-life decisions.

7.4.3 Implications for Education

From an educational perspective, it is evident that staff within ID services need more education in relation to end-of-life care, particularly in relation to clinical skills. Therefore, skills such as assessing symptoms at end of life effectively and managing the use of syringe drivers need to be delivered to this cohort. These skills could be taught using a combination of on-line education resources, with practical sessions to support learning and improve access.

Staff in acute hospitals need more education in relation to ID, particularly in relation to understanding the impact of specific syndromes or health conditions which have a particular impact on those with ID. Again, these skills could be taught using a combination of on-line education resources, with practical sessions to support learning and improve access.

Given that the majority of those responsible for providing end-of-life care in this study were nurses, ensuring that changes are made at undergraduate nursing level to ensure both general and ID nurses access education in relation to end-of-life care and ID, would appear to be an effective starting point for addressing some of the issues identified in clinical practice. However, not all the educational issues identified in this study were linked to deficits in medical and nursing knowledge. Strategies for effectively communicating with people with ID, also need to be delivered, in conjunction with educations resources which assist staff in promoting the autonomy of people with an ID and undertaking capacity assessments. Given the changes envisaged following the enactment of the ADM (2015), professional across all health services must be educated to ensure they are ready to integrate these legislative changes into clinical practice.

Some managers, who were pressing for changes in how supports were provided to the expanding population of older adults in ID services, had undertaken some form of postgraduate education in either gerontology or palliative care. These managers served as role models to their staff in many instances and led by example when it came to engaging in conversations about death, dying and end-of-life care, in particular. It is important that staff within ID specialist services are supported to engage in further postgraduate education, so they can effectively support the increasing number of older adults who will require end-of-life care in ID services. The continued education of staff to this level, could lead to the development of Clinical Nurse Specialist and Advanced Nursing Practitioner roles in ID and end-of-life. The availability of these specialist nurses, in conjunction with nurses and social care staff and allied professionals in specialist ID services, would help to address some of the issues caused by skills mix, identified in this study.

7.4.4 Implications for research

The need for continuing research in this area is evident. Firstly, given the changes envisaged in the ADM Act (2015), an intervention study focused on promoting a functional approach to autonomy, capacity and advance care planning would support the development of end-of-life care in specialist ID residential services. Such an intervention study would include people with an ID themselves, and those within their circle of support, including family members, both parents and siblings who, in the future, might be called on to support the individual at end of life. The intervention would focus on integrating comprehensive approaches to advance care planning into person centred planning processes and identifying how this can be done in such a way as to ensure that people with an ID, irrespective of their level of ID are included.

Such as intervention would also seek to identify how the collective knowledge of those within circles of support can be harnessed in a proactive way, to ensure the end-of-life will and preferences of people with an ID are identified.

Secondly, given that this study has identified that GPs and CPCTs have pivotal roles to play in supporting end-of-life care, further research, needs to be undertaken with these professionals in relation to their perspectives on supporting people with an ID at end of life. This research should be undertaken, in clinical settings across both community and acute care services, to identify the issues faced by these staff in a real world context. The extent of education provided, particularly to GPs and consultants in relation to ID, also needs to be explored, given that this study, has identified they play a central role in decision making at end of life.

Finally, this study identified that staff in acute hospital settings are heavily reliant on families and staff from specialist ID services when supporting people with an ID at end of life.

Further research needs to be undertaken to identify in detail, the issues facing people with an ID in hospital settings and those faced by staff in these acute settings when called upon to support people with an ID. These studies need to focus on some of the issues identified in this study, such as educational deficits in relation to ID, specific syndromes and the use of alternative forms of communication when supporting the person with ID at end of life. From a service perspective and in keeping with the current national focus on the integration of health and social care services, research needs to be undertaken to identify factors which promote and inhibit service integration between specialist ID and acute hospital services.

7.4.5 Policy Implications of Findings

Currently, within an Irish context, several health focused governmental policies have been launched including The Integrated Care Programme for Older People (ICOP, 2016) and The Future of Healthcare Sláintecare Report (Houses of the Oireachtas Committee on the Future of Healthcare 2017). Specific to palliative care, a report on Adult Palliative Care Services- Model of Care for Ireland was published by the National Clinical Programme for Palliative Care (2019).

The focus of these policies is to ensure that Ireland, in the future, will provide a universal, single-tiered health and social care service where everyone has equitable access to services based on need and not ability to pay. While the focus of these policies is to be welcomed, it is imperative that, when rolling out these polices, the specific needs of people with an ID at end of life are met.

This study has identified that health professionals in acute hospital settings need support to enhance their knowledge of the needs of people with ID, in order to provide effective care at the end of life. This must be addressed as part of Sláintecare (2017) to ensure that acute hospital services develop in a manner which improves access for people with an ID and ensure their needs are addressed within acute care services. This study has also identified that hospital services are heavily reliant on support for ID specialist services and family members when a person with an ID is admitted to hospital. In addition, this study has identified that people with an ID value the presence of those who know and understand their needs. Therefore, specialist liaison nursing roles in ID must be established within acute hospitals to support the person with ID, their family, and staff within the acute hospital setting. While Sláintecare (2017) commits to a service based on need, clinicians, researchers and advocacy groups such as Inclusion Ireland will need to continue to influence the development of these policies to ensure the specific needs of those with ID, as identified in this study, are met.

Issues such as ensuring that there is an appropriate skill mix within community-based specialist ID and palliative care services to meet the needs of people with an ID, have been identified in this study. The importance of the development of robust lines of communication and the need for ongoing collaboration and consultation within and between services, has also been emphasised in this study.

It is imperative that the integration of acute and community-based services, as envisaged under the Integrated Care Programme for Older People (2016) is undertaken in such a way as to ensure that the aforementioned issues within ID services are addressed. Further policy developments in this area need to make explicit reference to the integration of specialist ID settings, specifically since, as identified in this study, community based services which can be quite isolated often struggle to develop links across primary, secondary and tertiary care services. Given the fact that the majority of specialist ID services are provided by voluntary organisations, within community-based services, it is imperative that representatives of these service providers are involved in the roll out of these policies in conjunction with policy makers from the Department of Health and Department of Social Protection.

The reorientation of the health care services, as envisioned by Sláintecare (2017), from acute to community based services is also reflected in the Time to move on from Congregated settings Report (Health Service Executive Report, 2011), which outlined changes to service provision for people with an ID and is further reflected in the Adult Palliative Services, model of care for Ireland as developed by the National Clinical Programme for Palliative Care (2019). This model of care identified a need to consider how to extend palliative care services to vulnerable groups including those with an ID. However, a more explicit commitment to supporting people with an ID must be made to ensure that issues identified within this study such as skills mix within ID services, the training and education of staff in end-of-life care and enhanced access to specialist palliative care and hospice services area addressed. Failure to do so, will lead to the marginalisation of specialist services for people with an ID and the issues relating to the preparedness of ID services to provide end-of-life care, as identified in this study will not be addressed.

Currently, the ADM (2015) has yet to be enacted. However, in the interim period, policy documents are being developed to support families and staff, given the changes envisioned by the Act. Policies are being developed at a national level to inform staff and families about the changes which will occur as a result of the act, in particular, the change from a “best interest” to “will and preference” approach to decision making. It is imperative that staff and families are supported in developing communication strategies that enable people with an ID to express their will and preferences in a timely manner.

This study identified that people with an ID are not informed that they are dying in most cases, irrespective of their level of ability. Therefore, several distinct strategies must be put in place nationally and at local level to ensure the right of people with an ID to make autonomous decisions are upheld. Firstly, policies need to be developed to ensure staff and families fully understand the concept of a functional assessment of capacity and how it should be applied in a real world context. This study has identified that despite the development of the National Consent policy, issues relating to capacity, consent, autonomy and the role and rights of the individual involved, and their family

members are still not fully understood. A policy document specific to the needs of the person with ID and their circles of support needs to be developed. Education initiatives will also be required to ensure that the changes envisaged under the act, are integrated into service provision.

The communication needs of those with an ID will also need to be addressed to ensure that those who require significant supports to communicate have access to them. Augmentative and assistive communication strategies take time to put in place and time will also need to be provided to ensure people with an ID have enough time to formulate and express their will and preference. Therefore, it is imperative that appropriate supports are put in place, in a timely manner to ensure that people with an ID have their voices heard and it is not wrongly assumed that they lack the capacity to makes their wishes known. Therefore, an explicit policy relating to capacity, autonomy and communication for the ID population will need to be developed to ensure that families, health professionals and legal experts can support the autonomy of people with an ID.

The importance of relational autonomy in promoting the autonomy of people with an ID must also be embedded in policy documents at a national level. The role of families and significant others in supporting people with an ID to make changes will fundamentally change as we move from a Wardship based approach to the ADM (2015). The danger is that those within circles of support will feel that they no longer have a voice and will become marginalised. This study has identified that circles of support have a fundamentally important role to play in promoting the autonomy of people with an ID but the changes envisioned under the ADM (2015) will mean that those involved will need support and education to understand what their role is within the context of this changing legal landscape. Furthermore, specialist ID services must develop their own in service documentation to inform and support people with an ID, their families and staff on how best to promote the autonomy of people with an ID and support end-of-life decision making in a timely manner.

7.4.6 Study strengths and limitations

As with all empirical research, this study has both strengths and limitations. One of the strengths of this study is its use of a multiple case study design. This approach has allowed the presentation of findings related to end-of-life care and decision making from multiple perspectives from within and across specialist ID residential services and acute hospital settings. In doing so, it has captured the perspectives of families, staff and service managers as well as presenting concise overviews of the end-of-life care provided to the nine decedents in the two years prior to their deaths.

This study had availed of numerous methods of data collection and analysis including data gleaned from organisations, case files, interviews and questionnaires. The data from all of these sources has been integrated to provide thick descriptions of the end-of-life care of the nine decedents in this study.

This approach has facilitated a broad based description and analysis of end-of-life care and decision making practices in specialist ID residential services.

This study is one of the first of its kind, to chart the end-of-life care provided to people with an ID, from two years prior to their deaths and to comprehensively capture the perspectives of the families, staff and service managers supporting them. In addition, the organisational issues encountered when providing end-of-life care have also been identified. Thus, this study had presented, a holistic, multi-faceted and comprehensive analysis of end-of-life care supports and decision making practices, with specialist ID residential services.

In conjunction with these strengths there were also limitations to this study. The findings of this study are to a certain extent culturally bound, in that the three organisations in this study were all based in the Republic of Ireland. These organisations were also heavily influenced by the ethos of a social model of care and person centred planning. In addition, all organisations had access to palliative care support and CPCT, which might not be available to all ID organisations nationally and internationally. This study also focused on families and ID staff directly employed by and providing services within specialist ID residential services. Therefore, other professionals, based in services external to these specialist ID residential services, such as GPs, CPCT, and consultants, who, also provided significant supports were not interviewed.

From a methodological perspective, case study research lends itself, to providing a detailed overview of a specific issue, which limits the generalisability of the findings of this study. Additionally, the issue of researcher bias can have significant implications in the quality of the findings produced. The researcher in case study research is integral to the research process, and are in many ways, a research instrument in and of themselves. It is imperative, that researchers are conscious of and manage their own inherent bias, in order to present the findings of each study in an objective way. In this study, steps such as, the use of a case study database and reflective techniques were used to maintain objectivity.

To conclude, the main focus of case study research is not to ensure generalisable findings. Rather, it seeks to provide enough detailed information to allow those reading the cases, to translate the findings of the study, to their own practice or policy development initiatives. In this study, findings relating to issues identified in preparedness to provide end-of-life care, for example could support service managers in identifying both the on-going educational needs of their staff, and changes which may be required in providing clinical care. The findings could also assist them in identifying what policies and processes need to be put in place to ensure services are equipped to provide end-of-life care. The detailed manner in which the cases are presented in this study, should facilitate this.

7.4.7 Dissemination of findings

There is an onus and responsibility on researchers to disseminate the findings of their research, to ensure that services continue to improve and evolve. Some of the findings of this study were previously presented at the 19th International Nursing Ethics Conference 2018, in an oral presentation entitled *"End-of-life care provision and decision making practices with people with an intellectual disability from the perspectives of family members and frontline staff".* A presentation on case study research, was also presented to PhD students at a research day in University College Cork in August 2019. It is envisaged that further oral presentations will be undertaken in the dissemination of the findings of this study.

Most importantly, I am currently a member of the education committee, put in place by the Department of Health at national level, to review the role of ID nurses and their educational requirements and in this capacity, I will be seeking to promote the need for changes not just to ID nursing curricula, but also those of general nursing curricula to promote the development of services at end of life for people with an ID. There will also be opportunities to influence the development of postgraduate courses in this area.

Finally, it is envisaged that the findings of this study will be published in research journals relating to end-of-life care, ID, and ethics in the coming years and this thesis will also be available on electronic open research archives such as CORA, in University College Cork.

Planned Papers for 2020

1. *The importance of relational autonomy in supporting end-of life decision making for people with an ID* in the journal of Nursing Ethics
2. *End-of-Life Decision Making in Specialist Intellectual Disability Services* in Intellectual Disability Research

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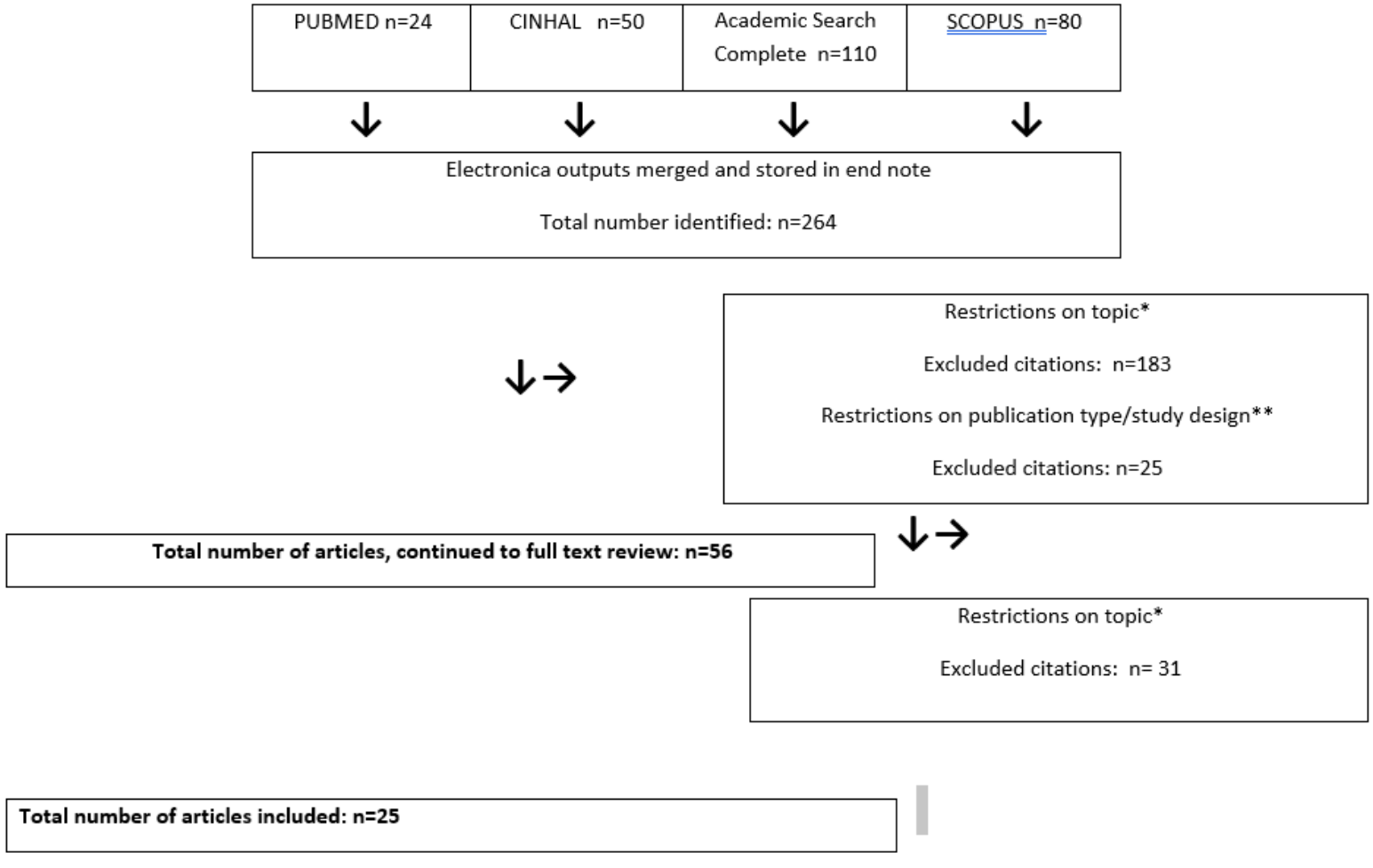
Appendix 1: Search Strategy

Date	2015-2018	
Research Topic	End-of life care and decision making practices in specialist ID residential services	
Search Strategy	**Keywords/concepts**	**Synonyms/alternative terminology (consider regional variations here also)**
	Search #1	intellectual dis* OR "cognitive* impair*" OR "cognitive impairment" OR "mental retardation" OR "mental handicap" OR "learning disability"
	Search #2	"End of life" OR "end-of-life" OR "palliative care" OR "end of life care" OR dying OR death or "death and dying" OR hospice
	Search #3	Family OR families OR "family member" OR guardian
	Search #4	"patient representatives" OR "paid carer*" OR "health professional* "healthcare worker" OR professionals OR "social care" OR "social care worker
Limits and type of material required	English language, excluding literature reviews, commentaries and editorials	
	Not later than 2003 (limit of 15 years)	
Databases and Resources searched	PubMed, CINAHL, Academic Search Complete, Scopus, Web of Knowledge,	
	Electronic hand search of journals specific to intellectual disability.	
Inclusion criteria	Empirical research only, relevant to intellectual disability population, end-of- life care, perspectives of people with an intellectual disability, perspectives of family members, perspectives of paid carers, focused on end-of-life decisions	
Exclusion criteria	Not empirical research, focused on dementia and/or acquired brain injury, focused on those with a disability other than an intellectual disability, focused on peri-natal and postal natal end-of- life issues, focused on children, focused on genetic factors in end of life or specific rare syndromes, position papers, editorials, literature reviews	

Search details	PUBMED	CINHAL	Academic Search Complete	SCOPUS
Search #1 intellectual dis* OR cognitive* impair* OR "cognitive impairment" OR "mental retardation" OR "mental handicap" OR "learning disability"	19,261	14, 138	95,562	19,797
Search #2 "End of life" OR "end-of-life" OR "palliative care" OR "end of life care" OR dying OR death or "death and dying" OR hospice	15,917	171,824	413,426	640,798
Search #3 Family OR families OR "family member" OR guardian	51,6802	210,021	693,675	872,583
Search #4 "health professional*" OR "healthcare worker" OR staff OR professionals	66,367	349,748	497,168	416,730
Search #5 decision making OR decision making OR advanced care	91,420	100,137	165,102	68,195
Search #1 and 2 ID and end of life	46	623	3,418	14
Search #1, 2 and 3 ID and end of life and family	16	92	538	119
Search #1, 2 and 4 ID and end of life and paid carers	7	80	465	8
Search #1, 2, 3 and 4 ID and end of life and family and paid carers	1	23	150	31
Search #1, 2, and 5 ID and end of life and decision making	9	65	183	38
Number of articles for review from combined searches	**79**	**883**	**4,754**	**210**
Total for review following screening and removal of duplicates	**24**	**50**	**110**	**80**


PUBMED n=24
CINHAL n=50
Academic Search Complete n=110
SCOPUS n=80
Electronica outputs merged and stored in end note
Total number identified: n=264
Restrictions on topic*
Excluded citations: n=183
Restrictions on publication type/study design**
Excluded citations: n=25
Total number of articles, continued to full text review: n=56
Restrictions on topic*
Excluded citations: n= 31
Total number of articles included: n=25

Appendix 2: Data Extraction Table

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Bailey, M., Doody, O., Lyons, R. (2014) Surveying community nursing support for persons with an intellectual disability and palliative care needs. *Learning Disability Practice, 44, p.24-34* Ireland	Total population of PHN, community nurses, practice nurse, hospice at home nurses and palliative care nurses in one HSE region Response rate of 32% (n=94)	Quantitative cross-sectional study	Questionnaire with some open-ended questions	Statistical and thematic analysis	85 people with an ID were referred to palliative care services over a 3-year period. Challenges including, understanding communication styles, late referrals, lack of time, knowledge and skills. Benefits of liaison between family professional and nonprofessional carers. Teamwork, advance planning, knowing the person was imperative	Specific to one HSE region in Ireland While the study focused on nurses, it included nurses with diverse qualifications and across services One of few studies in this area
Bekkema, N., Veer, A., Hertogh, C., Francke, A. (2014). Respecting autonomy in the end-of-life care of people with intellectual disabilities: A qualitative multiple-case study *Journal of Intellectual Disability Research, 58 (4), p368-80* Netherlands	47 people (14 family members and 33 staff who had supported 12 people with an ID who had died	Qualitative study	Semi-structured interview	Descriptive and thematic analysis	Respecting the right to autonomy was linked to transition points relating to new information on the diagnosis; changing needs and case wishes; and the importance of decisions. Greater issues arose in the promotion of the autonomy of people with severe ID than those encountered by people with a mild ID.	Retrospective study, so the experiences of those interviewed at the actual time the decedent was at end of life could not be ascertained. Experience of the decedent not identified 12 cases identified Perspectives of both families and staff included.

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Bekkema, N., Veer, A.J.E., Wagemans, A.M.A., Hertogh, C.M.P.M., Francke, A.L. (2014 a) Decision making about medical interventions in the end-of-life care of people with intellectual disabilities: a national survey of the considerations and beliefs of GPs, ID physicians and care staff. *Patient Education and Counselling, 96, p.204-209* Netherlands	Care staff ID physicians GP Response rate of 46% (n= 718)	Quantitative study	Developed questionnaire focused on respondent background and work related characteristics Considerations in decisions on medical intervention Personal beliefs	Statistical analysis Means and standard deviation ANVOVA Responses to open questions were coded	65.0% of respondents felt that the individual had a right to known and factors such as protecting the person, communication barriers and informing family members first impacted on this. People with a mild to moderate ID were consulted in 27.8% of cases and in 2.9% of cases for those with a severe level of ID. The wishes of family members were given greater consideration than the wishes of the person with ID.	Looked at actual considerations and personal beliefs Incorporated the perspectives of three groups Respondents were given a set of options to choose from which may have influenced the choices made. Retrospective study
Bekkema N., Veer A., Hertogh C., Francke, A. (2015). 'From activating towards caring': Shifts in care approaches at the end of life of people with intellectual disabilities. *BMC Palliative Care. 33. (10)* Netherlands	45 professional and relatives who had supported someone with an ID who had died.	Retrospective case study design	Semi structured interviews with professionals and families	Inductive and thematic analysis	Six values identified 1) 'Being there' and making extra time for the person 2) 'being responsive' to the person's real needs and possibilities. 3)'Reflection' on your own emotions, 4) 'Attentiveness' to the person's needs and wishes 5) 'Responsibility' for taking joint decisions 'openness to cooperation and sharing'	12 individual cases Retrospective study Both relatives and families included Made reference to the individual decedents

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Bekkema, N., de Veer, A. J., Hertogh, C. M., & Francke, A. L. (2016). Perspectives of people with mild intellectual disabilities on care relationships at the end of life: A group interview study. *Palliative Medicine*, *30*(7), *625–633* Netherlands	33 people with a mild ID in seven focus groups	Nominal group technique using qualitative approaches.	(1st interview) generations and recording of ideas 2nd interview Consolidation and confirmation of important factors	Qualitative thematic analysis	For people with a mild ID, ascertaining, recording and honouring the wishes of individuals are central to care relationships. The autonomy of those with an ID is not routinely respected. Terminally ill people with ID need other people to be there, in a practical, emotional, social and spiritual support from others.	One of few studies involving people with an ID. Focused on those with a mild ID only Small sample size None of those interviewed were receiving end of life care Many had completed a 'wish book', a book regularly used in Dutch ID care to write down someone's preferences for the funeral.
D'Haene, H. R. W., Pasman, L., Deliens, J., Bilsen, F., Mortier, R., Vander Stichele, R. (2010) End-of-life care policies in Flemish residential care facilities accommodating persons with intellectual disabilities. *Journal of Intellectual Disability Research, (54), 12, p. 1067-1077* Denmark. J	84 Residential care homes for people with an ID in Flanders	Quantitative study	Questionnaire and review of documents Questionnaire based on other studies focused on characteristics of the institutions and presence of policies	Statistical analysis and content thematic analysis	Twenty-nine (35%) of services indicated that they had such a policy available within their organisations. Sixteen services had a policy relating to palliative care, which included information on end of life decisions. Three had a policy on palliative care only; four services had separate polices on one or more end of life decisions, and two had policies relating to bereavement care.	Limited to residential care settings Limited number of services returned policies. Data collected in 2007

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Li, S., & Ng, J. (2008). End-of-life care: nurses' experiences in caring for dying patients with profound learning disabilities—a descriptive case study. *Palliative Medicine, 22(8), 949–955.* England	5 learning disability nurses working in residential services for people with an ID	Qualitative descriptive case study	Semi structured interviews	Interviews taped and transcribed, and thematic analysis undertaken	'Uncertainty of knowing', and ambiguity' about illness and death and issues relating to cultural and spiritual needs. Another theme related to 'certainty of knowing' which related to knowing the patient intimately, being able to identify their psychosocial needs and manage their symptoms; 'valuing' collaboration with palliative care teams and 'idealised image of a peaceful death'.	Small sample size Referred to nurse's perspective only
Marlow, S & Martin, J (2008) A voyage of grief and beauty': supporting a dying family member with an intellectual disability *International Journal of Palliative Nursing, (14), 7, p. 342-349* New Zealand	6 family members who supported a family member at end of life	Phenomenological research approaches	Interviews	Hermeneutic phenome-nological analysis	The journey when supporting a person at end of life was described as a voyage of grief and beauty; grief associated with anguish and vulnerability and beauty associated with the beauty of life and relationships with others.	Small sample size, Periods since bereavement ranged from 6 months to seventeen years therefore issues of recall could be a factor.

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
McCarron, M., McCallion, P., Fahey-McCarthy, E., Connaire, K. (2010) Staff Perceptions of Essential Prerequisites Underpinning End-of-Life Care for Persons with Intellectual Disability and Advanced Dementia. *Journal of Policy and Practice in Intellectual Disabilities (7), 2, p 143 – 152* Ireland	50 participants from ID services and 6 from palliative care services	Qualitative descriptive study	13 Focus groups	Thematic analysis with the development of core themes.	Two core themes emerged; themes: building upon services' history and personal caring by providing quality and sensitive care and supporting comfort and optimal death in persons with ID. Challenges included aging in place, person-centered care, and interservice collaboration.	Drawn from one specific area. Sample mainly comprised of those from ID services
McCarron, M., Burke, E.M., White, P., O'Dwyer, C., Ryan, K., O'Farrell, J., McCallion, P. (2018). "He'd mind you, you mind him". Experiences of end of life care for people with an intellectual disability as perceived by staff carers *IDS-TILDA, Trinity College Dublin* Ireland	28 carers were interviewed and information relating to 57 deceased people with an ID	Mixed methods study	Voices questionnaire administered as a semi structured interview Statistical data previously collated from IDS-TILDA project	Both quantitative and qualitative data delineated from the interview	Three themes were identified under the concept of relationship-based care namely; not joining up the dots, living the life one desired in one's last days and dealing with death and beyond. The willingness of staff to provide end of life care was indisputable.	Retrospective reporting of end of life care provided. Mixed method study which allowed for the cross checking of results. People in residential facilities were overrepresented.

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Morton- Stance, S & Schafer, T (2012) End of life care for people with a learning disability. *Nursing Standard, (27), 1, p. 40-47.* United Kingdom	6 nurses, 3 learning disability and 3 district nurses	Phenomenological qualitative approach	Open ended interviews	Collaizzi's seven stage process of thematic analysis	Five major themes identified Attitudes, good experiences, bad experiences, communication issues and future needs	Small sample Limited to one geographic area Two specialist areas represented, meaning a sample of 3 from each.
McKenzie, N., Mirfin-Veitch, B., Conder, J., Brandford, S., (2017). "I'm still here": Exploring what matters to people with intellectual disability during advance care planning. *Journal of Applied Research in Intellectual Disabilities (30) 6, p.1089-1098.* New Zealand.	Four people with an ID and a terminal diagnosis and family and service providers supporting them	In depth qualitative study	Two phased approach: (1) interviews with four people with ID, family members support staff. (2) follow up interviews of 2 people with ID and family and support staff	Thematic analysis	People with ID identified that planning their life (not only their death), making their own decisions, going at their own pace and openness and honesty were important to them. Family members and support staff identified that starting early and providing emotional supports for the person involved were central to the process of undertaking an ACP. Conflicting information caused confusion and having resources to guide them provided clarity.	One of few studies which interviewed people themselves Small sample size. One person was given hypothetical scenarios for parts of the ACP and so might have answered differently if told, he was discussing his own funeral arrangements. Level of ID of participants not identified but they had to be able to be interviewed suggesting a high functioning cohort.

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Ryan, K., McEvoy, J., Guerin, S., Dodd, P (2010) An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. *Palliative Medicine, (24), 6, p. 566-572* Ireland	ID and palliative care services staff Surveys and focus groups	Mixed methods	Questionnaire was attached to payslips and distributed with return enveloped. 91 individuals were purposively recruited to twelve focus groups.	Statistical analysis with Wilcoxon Friedman tests. Mann–Whitney and Kruskal–Wallis tests and content analysis	Both ID nor PC staff committed to providing end of life care for people with an ID but both groups were concerned about lack of knowledge and experience in these fields. Shared desire to cooperate with each other, but this was not enough to ensure services worked effectively. Communication issues, sharing of relevant practice knowledge and developing a consensus about care management needed to be addressed.	Large scale study across a number of disciplines All from one HSE area. Accessed via service managers No doctors responded to the survey but did attend focus groups. Limited generalizability as from one HSE area but the large sample size may mitigate against this.
Ryan, K., Guerin, S., Dodd, P., McEvoy, J. (2011). End-of-Life Care for People with Intellectual Disabilities: Paid Carer Perspectives *Journal of Applied Research in Intellectual Disabilities, 24, p 199-207* Ireland	64 participants from nursing, medicine, social work, physio, psychology, OT, complementary therapies, pastoral care, management, household staff	Qualitative	A topic guide was used to structure the interviews, tape recorded and analysed	'Framework' a content analysis guide developed by the National Centre for Social research	Both positive and negative impact of providing end of life care. Respondent found it rewarding and expressed satisfaction at ensuring that service users had a good death. Staff working in such settings lack the knowledge and resources to manage situations can become extremely stressed when service users did not have access to high quality care.	Large scale study across a number of disciplines No information provided as to how individuals were accessed. Limited generalizability as from one HSE area but the large sample size may mitigate against this.

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Todd, S (2013) Being there': the Experiences of Staff in Dealing with Matters of Dying and Death in Services for People with Intellectual Disabilities. *Journal of Allied Research in Intellectual Disabilities, 26, p. 215-230* United Kingdom	22 staff from five ID services in the UK, who had supported 29 people with an ID who had died.	Qualitative study	Semi-structured interviews	Qualitative thematic analysis	Impact of death in ID services considered different to other care settings as people with ID tend to be in these settings for longer, and the relationship between staff and service users can be more intense Respondents felt that the impact of death was not recognised by others within organisations. Being there was an important expression of respondent's commitment. Variety of transitions from living to dying, and to being remembered	Retrospective data Small sample size Specific type of service,
Tuffrey-Wijne, I., Bernal, J., Butler, G., Hollins, S., Curfs, L (2007). Using Nominal Group Technique to investigate the views of people with intellectual disabilities on end-of-life care provision. *Journal of Advanced Nursing, (58), 1, p.80-9.* United Kingdom	14 participants with a mild to moderate ID	Nominal group technique using both qualitative and quantitative approaches.	Generation of ideas, round robin recording of ideas; clarification of ideas, ranking	Ideas generated through discussion and ranked according to importance by the group	When afforded the opportunity people with an ID are happy to give their perspective on end-of-life care. Involvement in one's own care; Presence of family and friends; Offering activities to the ill person; Physical comfort measures were important	First significant study to include people with an ID Only those with a mild to moderate level ID could participate limiting the generalizability of the findings

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Tuffrey-Wijne, I., Whelton, R., Curfs, L., Hollins, S (2008) Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals. *Palliative Medicine, 22, p. 281-290* United Kingdom	543 professionals (57% response rate) working in specialist palliative care services	Quantitative study	Questionnaire consisting of demographic information and 28 potential issues which respondents were asked to rank	Data analysis using SPSS – Pearson chi-squared tests and one way analysis of variables	The study identified issues such as; patient's difficulties in understanding their illness, communication issues, issues impacting on assessment of patients' needs and fear experienced by individuals. The importance of collaboration between services and carers was important. People with ID seem to be referred to palliative care services late or if at all.	Specific to services in London More than one respondent could have answered basing their experience on supporting the same patient with ID Unsure of how many questionnaires were actually distributed
Tuffrey-Wijne, I., Bernal, J., Hollins, S (2010). Disclosure and understanding of cancer diagnosis and prognosis for people with intellectual disabilities: Findings from an ethnographic study. *European Journal of Oncology Nursing, 14, p 224-230* United Kingdom	13 people with an ID and a cancer diagnosis	Ethnographic study	3 years of data collection from "inside" the world of these individuals	Grounded theory analysis	Four significant themes: Truth telling and understanding were identified as imperative to ensuring the person was fully aware of what was happening. the importance of the role of families was identified. Issues with preparedness of both staff and services was an issue. Issues with living dependent lives and the importance of resilience.	One of few studies which involved research with people with an ID directly. Comprehensive overview of the lives of these individuals Not a representative sample and cannot be generalised to all people with an ID.

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Tuffrey-Wijne, I., Giatras, N., Butler, G., Cresswell, A., Manners, P., Bernal, J (2013) Developing Guidelines for Disclosure or Non-Disclosure of Bad News Around Life-Limiting Illness and Death to People with Intellectual Disabilities *Journal of Applied Research in Intellectual Disabilities, 26, p. 231-242* United Kingdom	109 people with an ID, family carers, ID professionals and medical health care professionals	Qualitative Interview schedule on experiences of breaking bad news; how people cope with bad news, whether they should be given bad news, who should break it	Focus groups and individual interviews	Content analysis using grounded theory procedures	People with an ID had varying perspectives on disclosure. Reasons for non-disclosure were to prevent distress, too difficult to break bad news for all concerned. Reasons for disclosure linked to rights, involving the person and helping the person to cope.	Large group of stakeholders and triangulation of data strengthens the study findings. Only those willing to consider discussing bad news could be invited to participate.
Tuffrey-Wijne, I & Rose, T (2017) Investigating the factor that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: an interview study. *Journal of Intellectual Disability Research 61 (1), 727-736* United Kingdom	20 social care workers from 8 services	Qualitative Semi-structured interviews	Interview guide developed for the study, with consultation from people with an ID, families and staff	Framework analysis procedure developed by Gale et al. 2013	Factors which impacted communicating bad news, include fear and distress around death, where people focused on their experiences of it, rather than their communicative approaches. The life and work experiences of staff impacted on how they communicated. Th persons cultural background and the organisational background also influenced communication	Focused on themes emerging from literature, leading to a stronger focus on pertinent issues. All staff based in London and all were social care workers limiting generalizability

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Wagemans, A., Van Schrojenstein Lantman-de-Valk H., Tuffrey-Wijne, I., Widdershoven, G., Curfs, L (2010) End-of-life decisions: an important theme in the care for people with intellectual disabilities. *Journal of Intellectual Disability Research (54), 6, p.516-524* Netherlands	Medical files of residents in a Dutch residential home who had died between 2002 and 2007	Retrospective review of the files of 47 cases of people with ID who had died in residential care	Checklist developed by the authors based on literature relating to end- of- life-care in people with ID .and some general literature.	Files were evaluated to establish how many end of life decisions were made, and each individual case is then presented.	30 of 47 cases death was expected. End of life decision made in 27 cases and no instance of euthanasia, assisted suicide without an explicit request from the person involved. In half of cases family member were involved, in the other half the individual had no other formal representative. Nurses were involved in all cases. Second opinion in 21 of the 27 cases.	Dutch law in relation to assisted suicide and euthanasia may influence the perspectives of those involved. Retrospective study Completed in one service. The perspectives of those involved in the decision making process were not recorded in their files and so cannot be established.
Wagemans, A., Van Schrojenstein Lantman-de-Valk H., Proot, I., Metsemakers, J., Tuffrey-Wijne, I., Curfs, L (2013) End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives. *Palliative Medicine, 27 (8), p.765-771* Netherlands	16 patient reps of 10 people with ID, professional carers involved with each individual and a medical professional	Qualitative study	Semi-structured interviews digitally recorded and analysed	Grounded theory procedures	Deciding for someone else, motivation for decisions, and supports provided were important Many representatives were unaware that the final legal decision was the doctors. Representatives doubted their loved ones had the capacity to decide about their health Doctors support was important but broke down where there were differences of opinion.	The authors did not identify the role of the professional carers involved. Role and responsibilities of those involved could have influenced their perspectives of the decision making process. The Netherlands have a system of ID specific physicians

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Wagemans, A., Van Schrojenstein Lantman-de-Valk H., Proot, I., Metsemakers, J., -Wijne, I., Curfs, L (2013 a). The factors affecting end-of-life decision making by physicians of patients with intellectual disabilities in the Netherlands: *Journal of Intellectual Disability Research, (57), 4, p.380-389* Netherlands	9 physicians involved in making end -of-life decisions for a person with ID	Qualitative study	Semi-structured interviews digitally recorded and analysed	Grounded theory procedures	Mainly focused on relatives' wishes and opinions: Involving relative's in decision-making. was important, and great weight was given to the opinions of families. Assessments of quality of life was delegated to family members Physicians sought consensus with other staff and family members and appeared to put greater weight on good working relationships than their own assessment of the patient's best	Retrospective study Small sample The Netherlands have a system of ID specific physicians which is not reflected in other jurisdictions.
Wiese , M., Stancliffe, R., Balandin, S., Howarth, G., Dew, A (2012) End-of-Life Care and Dying: Issues Raised by Staff Supporting Older People with Intellectual Disability in Community Living Services. *Journal of Applied Research in Intellectual Disabilities, 25, p.571-583* Australia	33 Direct care and middle management staff	Grounded theory study	Focus groups and face to face interviews	Theoretical sampling and constant comparative	End of life care impacted on by knowledge of dying, ethical values, the where of caring, the how of caring and post death caring. Also impacted by partners involved in the care of the individual both internal to and external to the community home involved.	12 individuals had not yet experienced a death Focused on staff only The personal; impact of death on individuals was not appraised Limited generalizability

Author /year /title /country of origin /journal	Sample/Setting	Research method	Data collection	Data analysis	Key findings	Strengths and limitations
Wicki, M & Hättich, A (2017) End-of-life decisions for people with intellectual disability – a Swiss survey. Switzerland International *International Journal of Developmental Disabilities, (63), 1, p. 2-7.* Switzerland	437 Directors of residential homes for people with disabilities with a 58% response rate	Cross sectional survey	Questionnaire developed based on a questionnaire developed by Wagemans et al (2010)	Chisquare tests and Mann–Whitney tests and Binary logistic regression	A prevalence rate of 70.4% was found for end of life decisions. For those with an ID decision made to abandon life prolonging treatment occurred more often (42.6%) when compared to those with other forms of disability (24.7%). The degree of disability, having an ID and having an advanced care directive were positively associated with a decision to withhold life sustaining treatment.	Retrospective study with potential for recall bias. Questionnaire were completed by care home managers, not physicians. Data set did not allow for inclusion of factors such as health conditions and prognosis which may have influenced decisions.

Appendix 3: Ethical Approval

UCC
Tel: + 353-21-490 1901
Fax:+ 353-21-490 1919

COISTE EITICE UM THAIGHDE CLINICIUIL
Clinical Research Ethics Committee

Lancaster Hall,
6 Little Hanover Street,
Cork,
Ireland.

Colaiste na hOllscoile Corcaigh, Eire
University College Cork, Ireland

Our ref: ECM 4 (aa) 06101115

17th December 2014

Dr Joan McCarthy
Lecturer
Catherine McAuley School of Nursing & Midwifery
University College Cork
BrookfieldHealth Sciences Complex
Co llege Rd d
Cork

Re: The quality of care and the decision-making processes involved in the end-of-life care of adults with an intellectual disability.

Dear Dr McCarthy

Expedited approval is granted to carry out the above study at:

Intellectual Disability Services in the Munster Region.

The following documents have been approved:

Signed Application Form
Detailed Study Protocol dated 8th December 2014
CV for Chief Investigator
Study Questionnaires
Information Leaflet/Consent Form for Health Professionals dated 8th December 2014
Information Leaflet/Consent Form for Family Members dated 8th December 2014
Information Leaflet/Consent Form for Interviews for Health Professionals dated 8th December 2014
Information Leaflet/Consent Form for Interviews for Family Members dated 8th December 2014
Information Leaflet/Consent Form for Service Providers dated 8th December 2014
Interview Questions dated 8th December 2014
Step-by-Step Process for Contacting Relatives.

We note that the co-investigators involved in this study will be:

Dr Nicola Carnally, Professor Willie Molloy and Ms Caroline Dalton, PhD Candidate.

[redacted]
Profes[redacted]
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

Appendix 4: Protocol for contacting families and frontline staff

Family Members

1. Initially, family members are contacted by the direct contact person within each organisation to make the family aware of the nature of the research study and identify if the family members are interested in participating in the study.
2. Should family members indicate they wish to be involved in the study the direct contact person within the organisation will post documentation pertaining to the study to the family on behalf of the researcher. This documentation will include a letter of introduction from the researcher, an information leaflet relating to the study and a consent form for each family member.
3. Should the family member decide to participate in the study, they return the consent form and their contact details to the researcher in the stamped addressed envelope provided. From this point on, contact is directly between the researcher and the family member not the organizations contact person.
4. The researcher phones the family member to establish direct contact with the person.
5. When phoning the family member, the researcher,
    a. Introduces herself.
    b. States that she is calling to follow up 'on a letter you received from XXX' {name of direct contact person within the organisation}.
    c. The researcher answers any further questions the family member may have.
    d. The researcher asks if the family member is still willing to participate in the study
6. Should the family member indicate that they still wish to participate in the study the researcher will organise to meet and interview the individual at a time and in a location convenient to the family member.

Frontline staff

7. Having established that the family member is willing to participate in the study, frontline staff who supported the deceased person must then be contacted.
8. Initially, frontline staff are contacted by the direct contact person within each organisation to make them aware of the nature of the research study and identify if the frontline staff are interested in participating in the study.

9. Should frontline staff indicate they wish to be involved in the study the direct contact person within the organisation will post documentation pertaining to the study to the frontline staff on behalf of the researcher. This documentation will include a letter of introduction from the researcher, an information leaflet relating to the study and a consent form for each frontline staff member.
10. Should the frontline staff member decide to participate in the study, they return the consent form and their contact details to the researcher in the stamped addressed envelope provided. From this point on, contact is directly between the researcher and the frontline staff member not the organizations contact person.
11. The researcher phones the frontline staff member to establish direct contact with the person.
12. When phoning the frontline staff member, the researcher,
    a. Introduces herself.
    b. States that she is calling to follow up 'on a letter you received from XXX' {name of direct contact person within the organisation}.
    c. The researcher answers any further questions the frontline staff member may have.
    d. The researcher asks if the frontline staff member is still willing to participate in the study.
13. Should the frontline staff member indicate that they still wish to participate in the study the researcher will organise to meet and interview the individual at a time and in a location convenient to the frontline staff member.

Appendix 5: Family Letter of Introduction

Dear _____,

My name is Caroline Dalton and I am currently a lecturer on the BSc Intellectual Disability Nursing Programme in the School of Nursing and Midwifery, University College Cork. Previous to this I trained and was employed as a staff nurse in COPE Foundation for twelve years. My specific area of interest is in the field of intellectual disability and particularly in relation to how end-of-life care is provided for people at this vulnerable time in their lives and in their families' lives.

I am writing to you to make you aware of my study which seeks to explore the quality of the end-of-life care provided to individuals, such as your loved one. I respectfully request your participation in this study, to explore your opinions and feelings in relation to the end-of-life care provided for your loved one and how decisions were made in relation to their care.

This study, which I am undertaking as a PhD student will be conducted under the supervision of Dr. Joan McCarthy (UCC), Professor. Willie Molloy (UCC) and Dr. Nicola Cornally (UCC). Included with this letter is an information leaflet explaining exactly what the study is about and what would be entailed if you were to agree to participate in the study. If you would like further information, I have provided my contact details.

Should you wish to participate in this study, please sign the consent form provided and return it to me in the pre-paid addressed envelope provided. Alternatively, you can contact me at the phone number or email address provided. Please be assured that COPE Foundation has not provided me with your contact details. The organization has kindly agreed to forward the information relating to this study to you, on my behalf.

Thank you for taking the time to read this letter and the attached information leaflet. If you have any queries or require additional information in relation to this study, please do not hesitate to contact me.
Kind regards,

_____

Caroline Dalton, RNID

PhD Candidate (contact details removed for confidentiality purposes)

Appendix 6: Family Information Leaflet

In Ireland, there are 27, 691 people with an intellectual disability and of those 7, 706 (27.8%) are aged between 35 and 54 years with 3, 675 (13.3%) aged 55 years or over (Kelly &Kelly, 2013). The age profile of people has changed over past decades with the proporation of those aged 35 yrs or over increasing from 29% to 49% since 1974. This changing profile has led to increased demand for services equipped to meet the needs of older individuals with an intellectual disability (Kelly& Kelly, 2010). In addition, organizations supporting individuals with an intellectual disability are now challenged to meet the end-of-life- care needs of these individuals and address associated issues (Ryan et al, 2011).

I am presently undertaking a PhD in Nursing, through the School of Nursing and Midwifery, University College Cork. I have a specific interest in the field of intellectual disability, particularly in relation to how end-of-life care is provided for people at this vulnerable time in their lives and in their families' lives. I am requesting your participation in this study, to explore your opinions and feelings in relation to the end-of-life care provided for your loved one and how decisions were made in relation to their care.

What is the purpose of this study?

The aim of this study is to describe the end-of-life care provided to people with an intellectual disability in Ireland. The study will explore how end-of-life care is provided for people with an intellectual disability, such as your loved one and identify the challenges experienced from the perspective of your family and the healthcare professionals who cared for your loved one at the time.

Specific research aims are to:

- Describe the end-of-life care of people with an intellectual disability in residential settings in Ireland.

- Determine the current advance care planning practices and end-of-life care of people with an intellectual disability.

- Identify key issues and challenges surrounding advance care planning and end-of-life care of people with an intellectual disability from the perspective of family and healthcare professionals.

What is involved in the study for you?

Participation in this study is completely voluntary and you can withdraw or refuse to participate in this study should you wish to do so. Should you agree to participate in this study, you are asked to attend for an interview of approximately one hour's duration. Interviews will be audio recorded. You will also be asked to complete the *Quality of Dying and Death questionnaire (QODD) – family member's questionnaire.*

The medical records of your loved one will also be reviewed to access information in relation to their end-of-life care such as medications, pain and symptom management.

Support for study participants

On occasion, while participating in the study, individuals may experience some emotional distress. Contact details for the research team will be provided and for those who request support in completing the forms, this support will be provided. If you become distressed during the course of completing the survey form, you will be given the opportunity to stop. Alternative dates will be identified if you feel unable to continue on the day but wish to complete the survey at a later date. Should you make the decision not to continue, you can withdraw from the study? In addition, you will be provided with information and contact details for bereavement support groups.

Will my information be kept confidential?

Yes, all information provided during the course of this study will be treated with the upmost confidence. Each individual will be identified by a numerical code therefore your anonymity is protected throughout the study.

Who might benefit?

It is hoped that the outcome of this study will inform developments in practice and lead to greater understanding of person centred decision making in end -of–life care for those with an intellectual disability and their families. This deeper understanding should lead to enhanced communication and better quality end-of-life care for individuals with an intellectual disability and their families.

Thank you for taking the time to read this information leaflet. Should you wish to discuss the study further or have any queries please contact Caroline Dalton at c.doconnor@ucc.ie or at (021) 4901455

Appendix 7: Consent Form for Families

I _____ have read the information relating to this study and I understand it.

(Print Name)

I am aware that there is no direct benefit or risk to me if I take part in this research study. I understand that the records associated with this study will be kept confidential. I understand that participation is entirely voluntary and that I can withdraw from the study at any point should I wish to do so.

I agree to be interviewed in relation to end-of-life-care.

I agree to complete the ***Quality of Dying and Death questionnaire (QODD) – family members.***

I agree to the review of my relative's medical records.

_____ _____

Signature of Participant ***Date***

Contact address: _____

Phone number: _____

Email address: _____

Appendix 8: Staff Letter of Introduction

Dear _____,

My name is Caroline Dalton and I am currently a lecturer on the BSc Intellectual Disability Nursing Programme in the School of Nursing and Midwifery, University College Cork. Previous to this I trained and was employed as a staff nurse in COPE Foundation for twelve years. My specific area of interest is in the field of intellectual disability and particularly in relation to how end-of-life care is provided for people at this vulnerable time in their lives and in their families' lives.

I am writing to you to make you aware of my study which seeks to explore the quality of the end-of-life care provided to individuals with an intellectual disability. I respectfully request your participation in this study, to explore your opinions and feelings in relation to the end-of-life care provided for individuals you have supported and how decisions were made in relation to their care. This study, which I am undertaking as a PhD student will be conducted under the supervision of Dr. Joan McCarthy (UCC), Professor. Willie Molloy (UCC) and Dr. Nicola Cornally (UCC). Included with this letter is an information leaflet explaining exactly what the study is about and what would be entailed if you were to agree to participate in the study. If you would like further information, I have provided my contact details.

Should you wish to participate in this study, please sign the consent form provided and return it to me in the pre-paid addressed envelope provided. Alternatively, you can contact me at the phone number or email address provided. Please be assured that COPE Foundation has not provided me with your contact details. The organization has kindly agreed to forward the information relating to this study to you, on my behalf.

Thank you for taking the time to read this letter and the attached information leaflet. If you have any queries or require additional information in relation to this study, please do not hesitate to contact me.

Kind regards,

_____

Caroline Dalton, RNID

PhD Candidate (contact details removed for confidentiality purposes)

Appendix 9: Staff Information leaflet

In Ireland, there are 27, 691 people with an intellectual disability and of those 7, 706 (27.8%) are aged between 35 and 54 years with 3, 675 (13.3%) aged 55 years or over (Kelly &Kelly, 2013).

The age profile of people has changed over past decades with the proporation of those aged 35 yrs or over increasing from 29% to 49% since 1974. This changing profile has led to increased demand for services equipped to meet the needs of older individuals with an intellectual disability. (Kelly& Kelly, 2010). In addition, organizations supporting individuals with an intellectual disability are now challenged to meet the end-of-life- care needs of these individuals and address associated issues (Ryan et al, 2011).

I am presently undertaking a PhD in Nursing, through the School of Nursing and Midwifery, University College Cork. I have a specific interest in the field of intellectual disability, particularly in relation to how end-of-life care is provided for people at this vulnerable time in their lives and in their families' lives. I request your participation in this study exploring the quality of care and the decision making processes involved in the end-of-life care of adults with an intellectual disability.

What is the purpose of this study?

The overarching purpose of this study is to describe the quality of care and the decision making processes involved in the end-of-life care of adults with an intellectual disability in Ireland. Specific research aims are to:

- Describe the quality of end-of-life care of people with an intellectual disability in residential settings in Ireland.
- Determine the current advance care planning practices and end-of-life care of people with an intellectual disability.
- Identify key issues and challenges surrounding advance care planning and end-of-life care of people with an intellectual disability from the perspective of family and healthcare professionals.

What is involved in the study for you?

Participation in this study is completely voluntary and you can withdraw or refuse to participate in this study should you wish to do so. Should you agree to participate in this study, you are asked to attend for an interview of approximately one hour's duration Interviews will be audio recorded. You will also be asked to review three questionnaires.

Will my information be kept confidential?

Yes, all information provided during the course of this study will be treated with the upmost confidence. Each individual will be identified by a numerical code therefore your anonymity is protected throughout the study.

Who might benefit?

It is hoped that the results of this study will inform practice and research in end-of-life care. The potential future benefits of the study include new and valuable insights on the quality of end-of-care provided to people with an intellectual disability from the perspective of family members and the health care professionals involved. This knowledge will, hopefully, contribute to improving the care provided to individuals with an intellectual disability and their families.

Thank you for taking the time to read this information leaflet. Should you wish to discuss the study further or have any queries please contact Caroline Dalton at c.doconnor@ucc.ie or at (021) 4901455

Appendix 10: Consent Form for Staff

I _____ have read the information relating to this study and I understand it.

(Print Name)

I am aware that there is no direct benefit or risk to me if I take part in this research study. I understand that the records associated with this study will be kept confidential. I understand that participation is entirely voluntary and that I can withdraw from the study at any point should I wish to do so.

I agree to be interviewed in relation to end-of-life-care and end-of life decision making.

I agree to complete two questionnaires:

Staff Perceptions of End of Life Experience (SPELE)

Quality of Death and Dying (QODD)

_____ _____

Signature of Participant ***Date***

_____

Print Name

Contact address: _____

Phone number: _____

Appendix 11: Profile of Home Questionnaire

Profile of Home Questionnaire

1. How many residents are there in the home? _____
2. Describe how GP services are provided for residents (i.e. is it a single GP practice that provides cover for residents, is it the residents own GP from prior to entering the home who provides cover, who provides out of hours cover, e.g. Southdoc).

   _____
   _____
   _____
3. What are the local hospitals to which residents may be referred?

   _____
   _____
   _____
   _____
   _____
4. On how many occasions were residents admitted to hospital over the last year? (i.e resident was transferred to hospital and stayed overnight)

   _____
   _____
5. On how many occasions did a resident attend A&E in the last year? (i.e. resident was transferred to hospital A&E department but did not stay overnight, was not admitted)

   _____
   _____
6. For questions 5 and 6 above, how many of these transfers to hospital were initiated "out of hours" (i.e. by doctor unfamiliar with the resident)?

   _____
   _____
7. How many residents died over the last year? _____
8. How many of these deaths occurred in the home? _____
9. How many of the residents who died were transferred to hospital in the 3 months prior to their death, and why were they transferred?

   _____
   _____
   _____
   _____
   _____
10. How/ were residents followed up if hospital stay prolonged?

    _____
    _____
    _____
11. How is the home informed of a hospital death?

    _____
    _____
    _____
12. What are the existing Specialist Palliative Care services in your area?

    _____
    _____

Appendix 12: Chart Review Form

Patient Reference No.	Chart No.	LTC Facility
Review Complete by:		Date Completed:
Date of admission to LTC:		Date of Death:

Person and Setting

Age	Gender		Single room		Ward of Court			Scale of decline			Death		Cause of Death	MTS/ MMS	Barthel Index
	Male	Female	Yes	No	Yes	No	Not Documented	Slow	Gradual	Quick	Expected	Unexpected		Score /10 /30	Score /20
														Date	Date

Comorbidities	Interventions (3/12)					
Cancer ☐ Dementia ☐ Stroke ☐ COPD ☐ Heart Failure ☐ Diabetes ☐ CKD ☐ Other ☐	Bloods Tests/X rays 1. 2. 3. 4. 5. 6. 7. 8. 9. 10.	Vital Signs (final recording) Date: Time:	GP Visits No of visits: Date of last visit:	IV/SC Therapy Yes / NO If Yes, state: Date commence Date Discontinued		Transferred to Hospital YES / NO If Yes, state: Date Length of stay	

Medications at End-of-Life

Review Drug Cardex for Past 3 months			Was dose changed If yes, included date		Was it stopped If yes, included date		How many doses missed in the past month	How many doses missed in the past week
Medication	PRN/REG	Start Date	Yes	No	Yes	No		

1 |

Pain and Symptom Management
(Please tick appropriate box)

Symptoms Documented in the last week of life	Yes	No	Medical Notes	Nursing Notes	Not Documented/comment
Pain					
Nausea/Vomiting					
SOB					
Anxious/Agitation/Restlessness					
Fatigue/Weakness					
Cough					
Seizure					
Hallucination/Nightmare					
Constipation/Diarrhoea					
Dry Mouth					
Secretions					
Other (Please state)					

Advance Care Directives/Planning

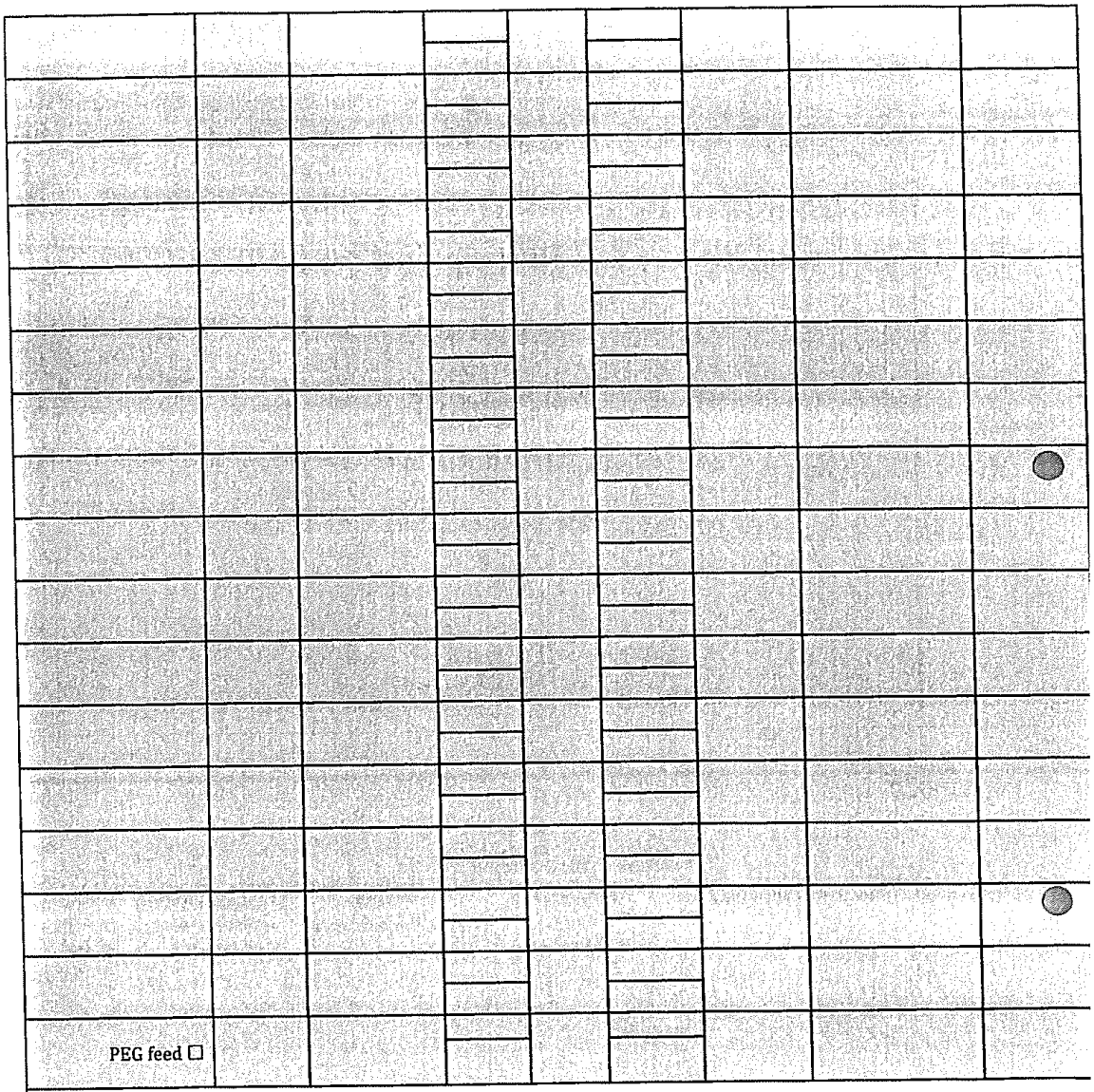
	Date Commenced	By Whom	Adhered to			Complication with adherence
Advance Care Plan Yes ☐ No ☐			Yes☐	No☐	Partially☐	
Advance Directive (LMD) Yes ☐ No ☐			Yes ☐	No☐	Partially☐	
End of Life Care Pathway Yes ☐ No ☐			Yes☐	No☐	Partially☐	
Do not Resuscitate order in place Yes ☐ No ☐			Yes☐	No☐	Partially ☐	

Patient/Family Distress

Was patient aware they were dying? Yes ☐ No ☐ Not Documented ☐	Sacrament of the Sick
Was the patient described as comfortable? Yes ☐ No ☐ Not Documented☐	
Was the family aware? Yes ☐ No ☐ Not Documented☐	Yes ☐ No ☐
Were the Family provided with a quiet/private room and facilities? Yes ☐ No ☐ Not Documented☐	
Were the Family Present at the time of Death? Yes ☐ No☐ Not Documented ☐	
When was it recognised that the patient was dying? No of Days ☐ Not Documented ☐	If yes, date received:
Was the patient reviewed by the Palliative Care Team (Specialist)? Yes ☐ No☐ Not Documented ☐	

Additional Notes:

Nurses in Charge of Care:



Supplements:

Infusion Driver Yes ☐ No ☐

Date Commenced:	By Whom:	Contents:	Date Discontinued:
		Morphine Yes ☐ No ☐ **Hyosine** Yes ☐ No ☐ **Medazolam** Yes ☐ No ☐ **Other** Yes ☐ No ☐	

Appendix 13: Quality of Death and Dying Questionnaire (QODD)

Section A:

		I am his or her.....							
A.1	What is your relationship to the person who died?	Husband or wife ☐	Partner ☐	Child ☐	Brother ☐	Sister ☐	Other relative ☐	Friend ☐	Other ☐

A.2	Are you male or female?	Male ☐	Female ☐
A.3	How old are you?	years	
A.4	Did you get to spend time with your relative or friend in their last week?	Yes ☐	No ☐
A.5	Were you with your relative or friend when they died?	Yes ☐	No ☐

Section B: Experience of where your relative or friend died

B.1	In what kind of room, did your relative or friend die?	Single room ☐	Shared room ☐	Don't know ☐
B.2	In what kind of room do you think your relative or friend would have liked to have died?	Single room ☐	Shared room ☐	Don't know ☐

B.3	Did the type of room where your relative or friend died affect the quality of how he or she died?	Not at all ☐	Mildly ☐	Moderately ☐	A lot ☐	Extremely ☐

	Please rate the following with regard to where your relative or friend spent most of their time in their last week of life	Very poor	Poor	Average	Good	Very Good	Don't know
B.4	The space where you could talk privately with staff	☐	☐	☐	☐	☐	☐
B.5	The space where you could talk privately with your relative or friend	☐	☐	☐	☐	☐	☐
B.6	You could stay as long as your relative or friend wanted you to	☐	☐	☐	☐	☐	☐
B.7	How did staff respond to your queries or requests	☐	☐	☐	☐	☐	☐
B.8	What did you think of the quality of care provided by the staff	☐	☐	☐	☐	☐	☐

Section C: Quality of life in the last week

The following questions are about your relative or friends experience during their last week of their life.
Please answer each question even if they were unconscious for some or all of the time.
Some of the questions relate to problems such as a person's ability to eat or drink, control going to the toilet or their ability to communicate. For some people such as people with advanced dementia, these may have been problems for many months, if this was the case for your relative or friend, please indicate when they last would have had no problem in that area.

C.1a	Did your relative or friend have physical pain?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any comments:								

C.2a	Was your relative or friend able to eat or drink?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.3a	Was your relative or friend able to breathe comfortably?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.4a	Did your relative or friend seem comfortable and at ease?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.5a	Did your relative or friend seem anxious or afraid?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.6a	Did your relative or friend smile, laugh or show signs of enjoyment in their last week?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.7a	Did your relative or friend seem to have the energy to do most of the things that they wanted to do?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments								

C.8a	Was your relative or friend able to physically control when they went to the toilet?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.9a	Was your relative or friend's dignity and self respect maintained?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.10a	Was your relative or friend helped to spend time with their family in the way they wanted to?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.11a	Was your relative or friend helped to spend time alone in the way they wanted to?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.12a	Did your relative or friend seem worried about causing strain to his or her loved ones?	None of the time ☐	A little of the time ☐	Some of the time ☐	A good bit of the time ☐	Most of the time ☐	All of the time ☐	Don't know ☐
Any Comments:								

C.13a	Did your relative or friend have his or her loved ones around them in the last week of life?	Yes ☐	No ☐	Don't know ☐
Any Comments:				

C.14a	Did your relative or friend say goodbye to their loved ones?	Yes ☐	No ☐	Don't know ☐
Any Comments:				

C.15a	Did your relative or friend seem to have meaning and purpose in their life?	Yes ☐	No ☐	Don't know ☐
Any Comments:				

C.16a	Did your relative or friend have any money worries, such as the cost of care?	Yes ☐	No ☐	Don't know ☐
Any Comments:				

C.17a	Did your relative or friend have one or more visits from a religious or spiritual advisor such as a priest?	Yes ☐	No ☐	Didn't want these visits ☐	Don't know ☐
Any Comments:					

C.18a	Was anyone there at the moment of your relative or friends death?	Yes ☐	No ☐	Don't know ☐
Any Comments:				

C.19a	In the moment before your relative or friend died, were they	Alert ☐	Semi-conscious but able to speak ☐	Unconscious ☐	Don't know ☐
Any Comments:					

C.20	Overall how would you rate relative or friends quality of life during their last week?	1 = Terrible 10 = Almost perfect 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	Don't know ☐

C.21	Had your relative or friend made funeral plans?	Yes ☐	No ☐	Don't know ☐

C.22	How well did staff (doctors and nurses) communicate with your relative or friends about their illness?	1 =Very Poorly 10 = Excellent 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	Don't know ☐

C.23	How well did staff communicate with you and your relative or friends family about his or her illness and death?	1 =Very Poorly 10 = Excellent 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	Don't know ☐

C.24	How well did staff provide end of life care that respected your relative or friends wishes?	1 =Very Poorly 10 = Excellent 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	Don't know ☐

C.25	Did your relative or friend discuss with their doctor or other staff how they wanted to be cared for at the end of life?	Yes ☐	No ☐	Don't know ☐

C.26	If no, did the doctor or staff looking after your relative or friend ask what care at the end of life your relative or friend would have wanted?	Yes ☐	No ☐	Don't know ☐

C.27	Were you expecting your relative or friends death?	Yes ☐	No ☐	Don't know ☐

C.28	Did you feel prepared for your relative or friends death?	Yes ☐	No ☐	Don't know ☐

C.29	Would you have liked more information on what to expect as someone is dying or what to do afterwards?	Yes ☐	No ☐	Don't know ☐

C.30	Overall how would you rate the quality of your relative or friends death?	1 = Terrible 10 = Almost perfect 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	Don't know ☐

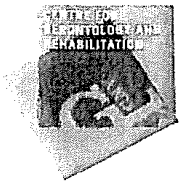
Section D: Comments on the care of your relative or friend

F.1 What went well in the care of your relative or friend during their last week of life?

F.2 What did not go so well in the care of your relative or friend during their last week of life?

F.3 Are there any other comments you would like to add?

Appendix 14: Staff Perceptions of End-Of-Life (SPELE



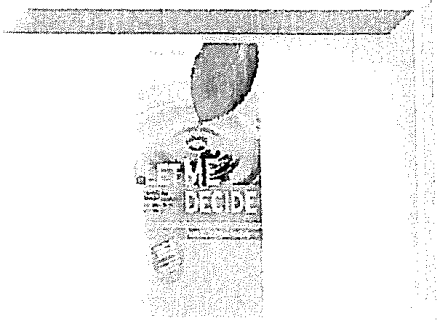
Staff Perception of End of Life Experience (SPELE) – Questionnaire

Centre for Gerontology and Rehabilitation, UCC

'Let Me Decide' Advance Care Directive and Palliative Care Research Programme

Contents:

- Information Leaflet
- Consent Form
- Questionnaire (SPELE)



Staff Perception of End of Life Experience (SPELE) – Questionnaire

These questions relate to your perception of the quality of care [Insert Residents Name] received during last week of life and other aspects of their dying and death. It is understood that you were not with the resident during the entire dying period: therefore we are seeking your overall perception. Please reflect on the resident's experience and answer as best you can.

Section 1: About You

1. What is your role? Staff Nurse ☐ Health Care Assistant ☐ CNM ☐ CNS ☐ ANP ☐

2. What professional qualification/registration do you hold?
☐ RGN ☐ RM ☐ RPHN ☐ RNP ☐ RCN ☐ RNID ☐ RPN ☐
Not Applicable ☐ Other ☐

3. What is your level of professional education?
FETAC Level 5 ☐ Certificate ☐ Diploma ☐ Degree ☐ Higher/Postgraduate Diploma ☐ Masters ☐ Doctorate ☐

4. What is your age?
Under 30 ☐ 31-40 ☐ 41-50 ☐ 51-60 ☐ Over 60 ☐

5. Your gender Male ☐ Female ☐

6. What is your Nationality? _____

7. What is your Religion? _____

8. Have you received Palliative Care Education? Yes ☐ No ☐
If yes, please provide details (Course name, duration, date, qualification)
_____
_____

9. Have you received education on Advance Care Directives/Advance Care Planning? Yes ☐ No ☐
If yes, please provide details (Course name, duration, date, qualification)
_____
_____

Section 2: Person and Setting

10. Did the resident die in a single room? Yes ☐ No ☐

11. Were family/friends/relatives present at time of death? Yes ☐ No ☐ N/A ☐

12. In your opinion did the type of setting (i.e being in a single/shared room) affect the quality of care at end of life? Yes ☐ No ☐
If yes, please comment
_____

13. What was the rate of the resident's decline?

a) **Slow** ☐
(person's health declined over a number of months)

b) **Gradual** ☐
(person's health declined over a number of weeks)

c) **Quick** ☐
(person's health declined over a number of days/hours)

d) **Sudden** ☐
(person died suddenly)

14. Was the resident's death Expected? ☐ Unexpected? ☐

15. What was the resident's pre-morbid state/function in the last month of life?

Please 'tick' level of ability to communicate effectively and functional ability	
Communication	**Activities of Daily Living (ADLs)**
a. Able to communicate effectively☐	a. Independent with ADLs☐
b. Somewhat able to communicate effectively ☐	b. Some assistance required with ADLs☐
c. Unable to communicate effectively☐	c. Needed full assistance with ADLs☐

What was the resident's pre-morbid state/function in the last week of life?

Please 'tick' level of ability to communicate effectively and functional ability	
Communication	**Activities of Daily Living (ADLs)**
d. Able to communicate effectively☐	a. Independent with ADLs☐
e. Somewhat able to communicate effectively ☐	d. Some assistance required with ADLs☐
e. Unable to communicate effectively☐	f. Needed full assistance with ADLs☐

Section 3: Pain and Symptom Experience at End of Life

16. Please complete the following section, on pain and symptom experience during the last week of life, by ticking the appropriate box.

During the last week of life	Presence of symptom (please tick)		How much distress did this cause?					In your opinion how well was this symptom controlled/managed?				
Did the person have any of the following symptoms?	**No** ↓	**Yes** →	**None**	**A Little**	**Some**	**Quite a lot**	**Very much**	**Very Poor**	**Poor**	**Moderate**	**Well**	**Very Well**
Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Nausea/vomiting	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Shortness of Breath(SOB)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Cough	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Seizure	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Hallucination/nightmare	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Constipation	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Diarrhoea	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Agitation/restlessness	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Dry mouth	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Secretions	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Decreased appetite	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other_____	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

17. Overall how would you rate pain and symptom management during the resident's last week of life?

Poor				Excellent
1	2	3	4	5

Section 4: Residents Personal Acceptance, Insight and Control

18. Please complete the following section on your perception of the resident's personal acceptance, insight and control, by placing a tick in the appropriate box.

During the last week of life was the resident…	Don't Know/ NA	Never	Rarely	Sometimes	Most of the Time	All of the Time
comfortable and at ease	☐	☐	☐	☐	☐	☐
frightened	☐	☐	☐	☐	☐	☐
sad/crying	☐	☐	☐	☐	☐	☐
able to maintain their dignity and respect	☐	☐	☐	☐	☐	☐
at peace with dying	☐	☐	☐	☐	☐	☐
touched and loved	☐	☐	☐	☐	☐	☐
able to spend time with family/friends/relatives	☐	☐	☐	☐	☐	☐
If the person had a chronic disease such as dementia and lacked capacity or was in an unconscious state please skip the following section and continue to Question 20						
able to say goodbye to loved ones	☐	☐	☐	☐	☐	☐
able to laugh, smile or show signs of enjoyment	☐	☐	☐	☐	☐	☐
able to have control over what was going on around them	☐	☐	☐	☐	☐	☐
aware they were dying	☐	☐	☐	☐	☐	☐

19. Overall, how would you rate the person's acceptance, insight and control regarding their dying experience and death?

	Poor				Excellent
Please rate the following	**1**	**2**	**3**	**4**	**5**
Acceptance					
Insight					
Control					

Section 5: Resident's Preferences

20. Was an Advanced Care Plan/Advance Care Directive in place?
Yes ☐ No ☐
(please circle to indicate whether it was an advance care plan or advance care directive)

If either was in place, was this adhered to? Yes ☐ No ☐ Partially ☐

Please comment

_____

21. How well do you think the residents....	**Don't Know**	**Not at all=1**	**2**	**3**	**4**	**Fully Met=5**
wishes were met	☐	☐	☐	☐	☐	☐
spiritual needs were met	☐	☐	☐	☐	☐	☐
religious beliefs and cultural practices were met	☐	☐	☐	☐	☐	☐

22. How would you rate the level of control the resident had in the decision making regarding their care, place of death and type of death?

No control				**Full control**	
1	**2**	**3**	**4**	**5**	**N/A (lacked capacity)**

23. How much control do you think the resident wanted in the decision making regarding their care, place of death and type of death?

No control				**Full control**	
1	**2**	**3**	**4**	**5**	**N/A (lacked capacity)**

Section 6: Communication

24. How would you rate the level of communication between the following people/groups?

Between....	Poor=1	2	3	4	Excellent=5	N/A
Resident and Healthcare Staff	☐	☐	☐	☐	☐	☐
Resident and Family/Friend	☐	☐	☐	☐	☐	☐
Healthcare Staff and Family/Friend	☐	☐	☐	☐	☐	☐

25. Was a team meeting held (formally/informally) to discuss the needs of the resident? Yes ☐ No ☐
If yes, how many days before the resident died?
_____

26. Was a palliative care specialist contacted?
Yes ☐ No ☐ Don't Know ☐
Did not have specialist palliative care needs ☐
Did not have access to specialist palliative care services ☐

If no, do you think they should have been contacted? Yes ☐ No ☐

If yes, how many days/hours before the resident died were they contacted?
_____

Section 7: Family Distress/Satisfaction

27. How satisfied do you think the family/friend/relatives were with the care provided?

Very Dissatisfied				Very Satisfied	
1	2	3	4	5	N/A

28. Did the family/friend/relatives appear distressed?

Very Distressed				Not Distressed	
1	2	3	4	5	N/A

29. Following the death were the family/friend/relatives given an opportunity to provide feedback?

Yes ☐ No ☐ Don't Know ☐ N/A ☐

30. How would you rate the level of support given to the family/friend/relatives at the end of life?

Poor				Excellent	
1	2	3	4	5	N/A

31. Were family/friend/relative offered information on what to do after the death e.g. bereavement services, if needed?

Yes ☐ No ☐ Don't Know ☐

Section 8: Global Rating of Care

32. Overall, how would you rate the quality of dying and death experience of your resident?

Poor				Excellent
1	2	3	4	5

33. Imagine the resident was you or a close family member. Would you find it acceptable to be cared for the way they were cared for at the end of life?

Totally Acceptable				Totally Unacceptable
1	2	3	4	5

Please comment on any issues raised by this questionnaire

_____

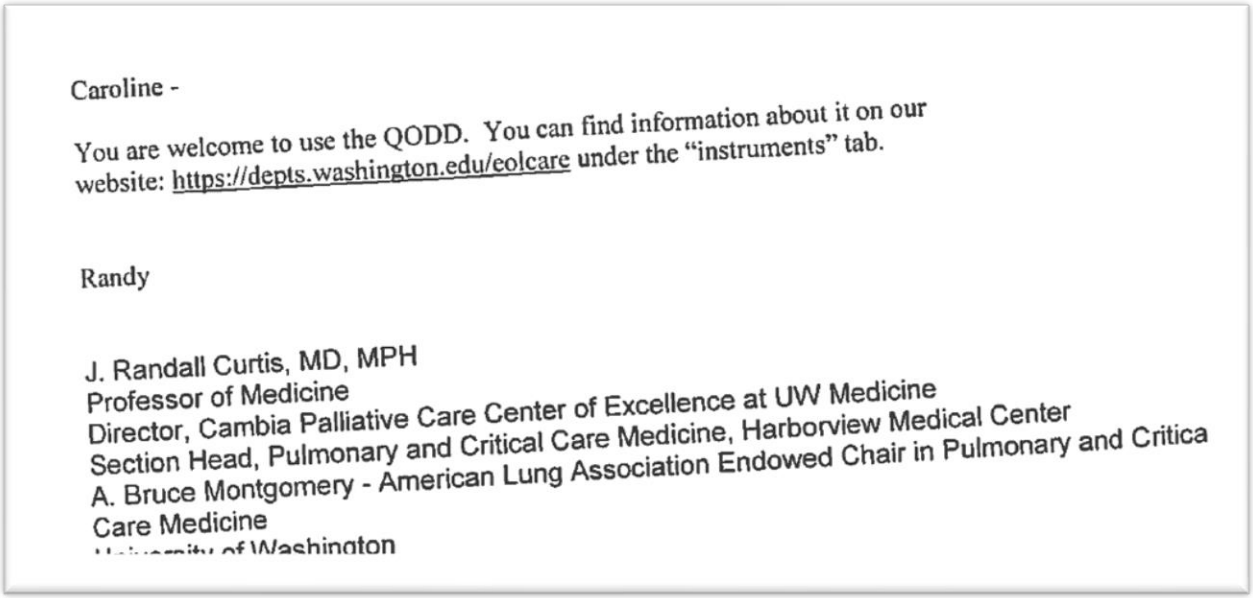
_____

_____

Thank you for completing this questionnaire

Appendix 15: Permissions to use Questionnaires

Permission gratefully received from Professor Curtis from the University of Washington



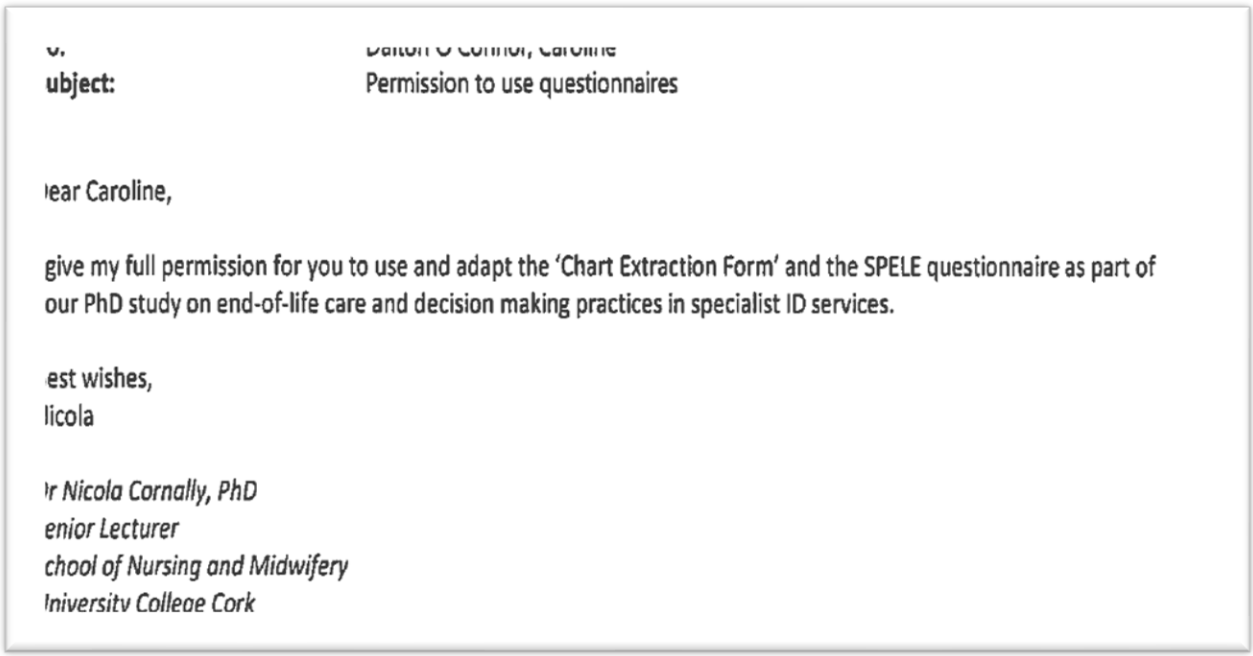
Caroline -

You are welcome to use the QODD. You can find information about it on our website: https://depts.washington.edu/eolcare under the "instruments" tab.

Randy

J. Randall Curtis, MD, MPH
Professor of Medicine
Director, Cambia Palliative Care Center of Excellence at UW Medicine
Section Head, Pulmonary and Critical Care Medicine, Harborview Medical Center
A. Bruce Montgomery - American Lung Association Endowed Chair in Pulmonary and Critica
Care Medicine
University of Washington

Permission gratefully received from Dr. Nicola Cornally



ubject: Permission to use questionnaires

ear Caroline,

give my full permission for you to use and adapt the 'Chart Extraction Form' and the SPELE questionnaire as part of our PhD study on end-of-life care and decision making practices in specialist ID services.

est wishes,
licola

r Nicola Cornally, PhD
enior Lecturer
chool of Nursing and Midwifery
Iniversity College Cork

Appendix 16: Interview Schedule for Families

1. Describe your experience of supporting a person with an intellectual disability in terms of their end-of-life care.
2. What are the key issues you feel need to be addressed in providing end-of-life care?
3. What challenges (if any) have you encountered in providing end-of-life care?
4. How were decisions relating to the person's care needs made?
5. Who was involved in the decision making process?
6. When were these decisions made?
7. To what extent was the person with the intellectual disability included in the decision making process?
8. How were issues relating to capacity and consent addressed?
9. Was the use of advanced care planning/directives ever discussed/ put in place?

The focus of the interviews should be in relation to:

A. A general statement to initiate the conversation around end-of-life care. Allowing those involved to discuss the death of the individual.
B. Identify what the issues are?
C. Elicit how communication occurred and how was the issue of consent addressed.
D. Then focus on ACD.
E. Then polices (dependent on whether it is a paid carer or family member).
F. Suggestions for the future—what would people like to see in the future, what should we do to make things better.

Appendix 17: Interview Schedule for Staff

1. Describe your experience of supporting a person with an intellectual disability in terms of their end-of-life care.
2. What are the key issues you feel need to be addressed in providing end-of-life care?
3. What challenges (if any) have you encountered in providing end-of-life care?
4. How were decisions relating to the person's care needs made?
5. Who was involved in the decision making process?
6. When were these decisions made?
7. To what extent was the person with the intellectual disability included in the decision making process?
8. How were issues relating to capacity and consent addressed?
9. Was the use of advanced care planning/directives ever discussed/ put in place?
10. What policies are in place within your organisation relating to end-of-life care and advance care planning?

The focus of the interviews should be in relation to:

A. A general statement to initiate the conversation around end-of-life care. Allowing those involved to discuss the death of the individual.
B. Identify what the issues are?
C. Elicit how communication occurred and how was the issue of consent addressed.
D. Then focus on ACD.
E. Then polices (dependent on whether it is a paid carer or family member).
F. Suggestions for the future—what would people like to see in the future, what should we do to make things better.

Appendix 18: Exemplar of Approach to Coding

Transcript	Condensed Data	Initial coding	Overarching Theme
Now a very funny thing, he was very extremely close to my mother and when I looked after my mother and my father at the end of their lives. But looking back on it I can remember and it used to upset me terribly and I used to worry in case she would hear him, he used to go in to the bedroom and he used to say don't die mom, so obviously he knew whether she said it to him, don't die at all mam and he would go out again, you know. F: he was twenty and he died as a result and I was badly injured but Johnny never spoke of him again, never. And I often brought him to the cemetery with me and I would say to him who is in there Frank, I don't know, and I would say to him do you remember (family members name) and it wouldn't be all that mighty long like do you know. No he didn't want to know and exactly the same thing happened when my mother died. He just as if she never ever existed so obviously he would have had a concept of death. Now we brought him to their funerals because at the time we would be at a loss to what to do and we said like he would be wondering where she went if he doesn't go to the funeral, you know. So we brought him to both their funerals and he never mentioned them again or at the stage when (family members name) died now he would have been quite mobile at that stage. And he could walk and everything and he would not come into the cemetery. He would sit in the car and he would not move, didn't want to know. So obviously he must have had some concept of his own impending death. Because I know there was an awful sadness in his eyes like and he had, like you would know they would catch your hands sometimes and you would know by him, he was trying to tell you something and it just wouldn't come and you have to sort of maybe say a dozen different things and then it would click.	he used to go in to the bedroom and he used to say don't die mom, **so obviously he knew** whether she said it to him, don't die at all mam and he would go out again, you know. No he didn't want to know and exactly the same thing happened when my mother died. He just as if she never ever existed so obviously **he would have had a concept of death**.	Awareness of death and dying Awareness of death and dying	Communicating Death Related Bad News

I: Okay. F: But so I feel he must have known something but we never said it to him but then you see he must have known when we were praying all the time and he was seeing the priest coming. Like he must have had some idea but because it would make you wonder why did he settle when they played the music to him. Like they said that he was sort of struggling up to that and he just faded away after that. So lots of things I suppose we'd never know, we will never know why or what. I: Did ye make the decision not to talk to him about it or was it just, you just didn't talk to him about it. F: Cover him at night, I mean they would go up and night and you know the way you would cover a baby and snuggle him down for the night and kiss him goodnight, that's how he was put to bed now he was nearly forty years of age. So we grew in to that, you see we never treated him as an equal as the most he was treated as an equal is when he went to {name of residential service}. He was like the baby in the family sort of where everybody fussed over him and you know like everybody protected him. So for that reason I would say that nobody in a million years any of the three wouldn't have said to him Ed you are going to die. You know because we would think we were hurting his, you know that we would think that we would upset him. So I would think that was the reason but because you are sort of saying we will do this tomorrow or do you know and we would be talking to him as if life was going to go on. And that was just protection, just protecting him for no other reason I'd say. I don't know what would have, how he would benefit for being told.	. He would sit in the car and he would not move, **didn't want to know.** So obviously he must have had some concept of his own impending death. He was like the baby in the family sort of where everybody fussed over him and you know like **everybody protected him.**	Not wanting to be informed. Protective instincts of siblings	

Appendix 19: Example from reflective diary

I completed an interview with Jennifer's sisters, Lorraine and Imelda, five days ago and they have been on my mind a lot since then. Both Lorraine and Imelda were very thorough in recounting Jennifer's end-of-life journey and the interview itself lasted an hour and a half.

A number of things struck me about the families' situation. Firstly, given the heredity nature of Jennifer's condition, she was not the only person in the family who had died from the condition. Lorraine told me when I phoned to discuss an interview time that other family members currently required 24-hour care for the condition. Both Lorraine and Imelda, had been tested for the condition and did not carry the gene.

When I arrived at the house, to interview them, three things became apparent very quickly. Jennifer, who was the older of the two, was very protective of Imelda, and from the way she spoke about Jennifer, it was clear that she had been very protective of her too. Jennifer was pragmatic and quite matter of fact about the impact of the diagnosis on the family and she had taken on the responsibility of organising the care of other family members, as she had done for Jennifer.

Imelda was a year older than Jennifer and they had been very close as siblings. She was very emotional when talking about Jennifer and it was clear from the way she recounted incidents from childhood that what happened to Jennifer had really impacted on her. She spoke of how Jennifer's behaviour began to change from the age of about seven, of how Jennifer would get into trouble at school despite Imelda's efforts to stop her doing so. She talked of how managing Jennifer became more difficult, as she would run away from the house, until it came to the point that Jennifer went into residential care. She broke down when she spoke of the day that she woke to find that Jennifer was gone and the impact of losing her closest friend. Imelda spoke of how her mother regularly visited Jennifer and took Imelda with her. She recounted an incident, when she had visited Jennifer, as a teenager in the company of her mother. She vividly described finding Jennifer in a distressed state, and she was unkempt and not appropriately clothed. She recalled her mother's distress, and the fact that she was openly crying. She remembered that a bitter argument had ensued between her mother and a doctor at the facility and that her mother had not spoken once on the bus journey home.

Imelda was emotional and crying at times during the interview and I found her story so difficult to listen to. She said that while she knew that Jennifer had been happy in the residential service where she had been cared for, she found it difficult to accept that she had to stay in residential care and seemed relieved in a way that she had died in the hospice.

Lorraine was more pragmatic about the care provided both to Jennifer and to her other siblings. Jennifer was continuing to monitor the needs of other family members and her knowledge of their condition was extensive. She had also linked in with a geneticist who was studying the condition in families. What struck me about her interview was that fact that she felt she was dismissed by health professionals when she tried to explain what had happened to other family members. Jennifer and Imelda came from a working class background and Jennifer felt she was not listened to because of this. This upset her greatly as she felt that the standard of care provided to others in the family would be improved if she was listened to. She also spoke of how little education some staff had in relation to the condition and that she sometimes found herself providing what to her, appeared to be very basic information.

Their interview upset me greatly. I was struck by what an amazing family they were given all they had already gone through and were still going through. In some instances, listening to them, I felt embarrassed as a nurse, as they recounted incidents of substandard care. I was also embarrassed that Jennifer, who had a wealth of knowledge built up on the condition, for over more than a decade, did not feel she was listened to. But mostly, I was upset for Imelda. The more I listened to the recording, the more evident her level of distress became to me, as things such as how ragged her breathing became, as she struggled to contain her emotions, were magnified by the quietness in the room where I listened to her interview. I spoke to her the day after the interview, as per the protocol, I had put in place and she assured me she was fine and that as a family they supported each other. I had also provided an information leaflet with contact details for support services and wondered would she contact any of them.

So far, I have listened to the recording twice this week, and find myself becoming emotional every time. I have started the process of pulling the information I collected from Jennifer's casefile and building the case study but I am finding this a difficult case to write.